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Investigating the transition to home experience for people with mild stroke: The Mild Stroke Transitional Experience in Australia

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Abstract

Background

Mild stroke was once considered a benign version of stroke, with minimal ongoing consequences for the person, or society at large. This perception has recently been challenged, with researchers identifying that people experience life changes as a direct consequence of a mild stroke event. Whilst research into the implications of mild stroke has started to grow, research into health services targeted to this population remains scarce. The transition period for people with mild stroke is particularly important to understand as it is a time in which they return to the community and engage in complex activities, and consequently when they start to identify changes that result from the stroke. By identifying this population's experience of the transitional period after stroke, healthcare services can be developed to meet their needs.

Research Aims

The purpose of this research was to determine the essence of the transition experience to home after acute hospital discharge for people with mild stroke and their key support people, under two different service models; an allied health-led, stroke specific self-management model of care that used telehealth, or 'standard care'. Two research questions were used to achieve this, with the first being 'How do people with mild stroke experience their transition home from acute hospital care?' and the second 'How do people experience the MiSTrEnGTH (Mild Stroke Enhancing and Guiding Transition Home) program in comparison to standard care?'

Methodology

A qualitative methodology was used in order to understand the 'essence' of the mild stroke experience. Interpretative phenomenological analysis (IPA), was guided by the tiered IPA methodology outlined by Smith, Flowers, and Larkin (2009) for the completion of PhD projects. The first study consisted of a longitudinal exploration of a spousal dyad across the first 9-months after mild stroke. The second and third studies involved five participants with mild stroke along the first 6-months after hospital discharge. The fourth study involved four key support persons who were interviewed at 9-months after hospital discharge. All participants were consecutively recruited and semi-structured interviews were recorded, transcribed verbatim and analysed by two research team members.

Findings

Findings from the first study revealed the transitional experience from the perspective of a spousal dyad. It highlighted that even in theoretically the best of contextual situations, people with mild stroke and their key support persons can experience changes to their lives following stroke. This finding was based on two themes: 'the unexpected, undesirable and short-lived' and 'the new normal'. The first of these indicated that there is a short period of time following the stroke where it

impacts on daily life. The second theme reflects the period following this where life returns to as it was before, but with subtle changes and lingering questions.

The second study extended the findings of the first and explored the experience of five people with mild stroke. The study identified that key contextual factors influence the impact of mild stroke on daily life. Such factors include society's perceptions of 'stroke' referred to as 'society determines the stroke experience', their past experiences titled 'the past determines the present', and their prior family dynamics indicated as 'underlying relationship dynamics revealed'.

Health experiences were explored with the same participants as the previous study, revealing three key themes. The first theme 'the difficult diagnosis' represents the issues participants experienced whilst trying to obtain a stroke diagnosis. The second 'standard care: good but not good enough', reflects participants' interactions with health services after discharge, observing that whilst they appreciated the standard care received, it was not good enough. The final theme portrays participants' appreciation for follow-up services and was titled 'a journey better not done alone'. For MiStrEnGTH participants this related to the allied health professional who contacted them, their general practitioner, and the RCT researchers. For 'standard care' participants, this referred to their general practitioner and RCT researchers.

The final study identified the experience of four key support people, by having them reflect on the first 9-months post hospital discharge. 'Activities gained but time lost' was the first theme identified, referring to the extra responsibilities they took on following the stroke, which limited their engagement in meaningful occupations. 'Subtle changes but big impacts' was the second theme which described the changes they observed in the person with mild stroke's behaviours and emotions.

Conclusions and Recommendations

The mild stroke experience is one that occurs within a certain context for each individual and it appears that for this population especially, it is important to consider this context as it contributes to ongoing implications in everyday life. Clinicians need to understand the person with mild stroke and their life in order to determine the consequences of the mild stroke for that person and direct intervention and services accordingly. Further research is required in regards to the diagnostic period, ongoing economic implications and transitional services for people with mild stroke.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

I acknowledge that an electronic copy of my thesis must be lodged with the University Library and, subject to the policy and procedures of The University of Queensland, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate School.

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Publications included in this thesis

Hodson, T., Gustafsson, L., Cornwell, P., & Love, A. (2017). Post-acute hospital healthcare services for people with mild stroke: a scoping review. *Topics in Stroke Rehabilitation, 24(4)*: 288-298. doi: 10.1080/10749357.2016.1267831

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). "Just got to live life as it comes": A case study of the spousal-dyad longitudinal mild stroke transitional experience. *Brain Injury, 33*(9). doi:10.1080/02699052.2019.1629625

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). The Lived Experience of Supporting People with Mild Stroke. *Scandinavian Journal of Occupational Therapy, Jul 2*, 1-10. doi:10.1080/1103828.2019.1633401

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). Unveiling the Complexities of Mild Stroke: An Interpretative Phenomenological Analysis of the Mild Stroke Experience. *The Australian Occupational Therapy Journal,* Advance online publication. doi:10.1111/1440-1630.12607

Submitted manuscripts included in this thesis

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). The Health-Care Experiences of People with Mild Stroke: An Interpretative Phenomenological Analysis. *Submitted to: Disability and Rehabilitation*

Other publications during candidature

Publications

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Conference Abstracts

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). Meeting the Needs of people with mild stroke: A tool to guide decision making. *Oral Presentation at Smart Strokes 2019, Hunter Valley, Australia, 8-9 August 2019.*

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Hodson, T., Gustafsson, L., & Cornwell, P. (2018). The Longitudinal investigation of the transition to home following a mild stroke – a case study of a spousal dyad. *International Journal of Stroke, 13*(IS), 34. Doi: 10.1177/1747493018778666. *Poster Presentation at STROKE2018, Sydney, Australia, 7-10 August 2018.*

Hodson, T., Gustafsson, L., & Cornwell, P. (2018). "Just got to live life as it comes": The Longitudinal spousal dyad experience of the transition to home following a mild stroke. *Poster Presentation at European Stroke Organisation Conference 2018, Gothenburg, Sweden, 16-18 May 2018*

Hodson, T., Gustafsson, L., Cornwell, P., & Love, A. (2016). Services for people with mild stroke following acute-hospital discharge: A scoping review. *International Journal of Stroke, 11*(IS), 5. Doi: 10.1177/1747493016661644. *Oral Presentation at Smart Strokes 2016, Canberra Australia, 25-26 August 2016.*

Contributions by others to the thesis

The PhD candidate was primarily responsible for: the design of the research included in this thesis, the obtainment of ethical approval, participant recruitment, data collection, data analyses and manuscript preparation.

The PhD candidate was assisted in this process by Professor Louise Gustafsson and Associate Professor Petrea Cornwell. Furthermore, Professor Louise Gustafsson and Associate Professor Petrea Cornwell provided critical appraisal of written work. Finally, Professor Louise Gustafsson contributed substantially to the completion and interpretation of data analyses.

Ms Amanda Love assisted with the critical appraisal of articles included within the scoping review chapter of this thesis.

To the best of my knowledge, all of the above persons who have contributed to this work have been acknowledged as authors. All others who have contributed to the work contained in this thesis but not at a level that constitutes authorship have been stated in the *Acknowledgements* section.




Tenelle Hodson Prof Louise Gustafsson A/Prof Petrea Cornwell Ms Amanda Love

Statement of parts of the thesis submitted to qualify for the award of another degree

No works submitted towards another degree have been included in this thesis.

Research Involving Human Subjects

Human research ethics approvals have been obtained from the MNHHS facility involved in the project, the University of Queensland, Griffith University (2015/884) and the Australian Catholic University in relation to the Randomised Controlled Trial associated with the project. An amendment to these ethics approvals to incorporate the qualitative component has been completed and approved by the University of Queensland (2016000021) and the MNHHS facilities (HREC/15/QPCH).

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Keywords

mild stroke, transitional experiences, interpretative phenomenological analysis, follow-up care

Australian and New Zealand Standard Research Classifications (ANZSRC)

ANZSRC code: 110904, Neurology and Neuromuscular Diseases, 10%

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Fields of Research (FoR) Classification

FoR code: 1109, Neurosciences, 10%

FoR code: 1117, Public Health and Health Services, 10%

FoR code: 1103, Medical and Health Sciences, 80%

Dedications

This thesis is dedicated to Greg Hodson, my Dad, my hero. You demonstrated and instilled in me the values of hard work, determination, and honesty, all of which contributed to the development of this work. Without your presence in my life this thesis would not exist and now that it does, you will forever be a part of it.

Contents

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List of Abbreviations

ABI	Acquired Brain Injury
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHP	Allied Health Professional
APA	American Psychological Association
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
KSP	Key Support Person
LG	Louise Gustafsson
LOS	Length of Stay
MiStrEnGTH	Mild Stroke: Engaging and Guiding Transition Home
PC	Petrea Cornwell
PwMS	Person with Mild Stroke
QoL	Quality of Life
RCT	Randomised Controlled Trial
SF	Stroke Foundation
SSMP	Stroke Specific Self-Management Program
TIA	Transient Ischaemic Attack
TH	Tenelle Hodson
WHO	World Health Organisation

Chapter 1: Introduction

This thesis seeks to identify the essence of the mild stroke transitional experience, following acute-hospital discharge. Chapter 1 provides an introduction to the thesis, including a brief rationale that will be expanded upon in Chapter 2. Following the rationale, the aims of the thesis are presented inclusive of key research questions. The chapter then concludes with an outline of the thesis structure.

1.1 Rationale for Thesis

People with mild stroke contribute to approximately half of the overall stroke population (Burns et al., 2018; Wolf, Baum, & Connor, 2009) yet have traditionally been overlooked in terms of post-hospital discharge care services (Tellier & Rochette, 2009). It has been identified that this population experiences difficulties that only become apparent when they begin to reintegrate into daily living and the associated complex activities (Tellier & Rochette, 2009). This time from acute hospital discharge back to home and community life can be identified as the transition period and for people with mild stroke it is one of the most influential times in the recovery continuum (Hall, Grohn, Nalder, Worrall, & Fleming, 2012). This is because it is a time in which their perceptions of themselves are challenged as difficulties emerge, resulting in a need to develop new routines and accept ongoing changes (Glass & Maddox, 1992; Goodman, Scholssberg, & Andersson, 2006; Hall et al., 2012). Difficulties experienced by this population span all domains of human functioning including: cognition, physical functioning and emotional well-being, consequently impacting the completion of daily activities (Taule & Råheim, 2014). It therefore appears that there is a gap in health services for people with mild stroke who may experience such ongoing difficulties that are not detected during the acute hospitalisation period (Burns et al., 2018). This gap in services may result from an inability to detect difficulties specific to mild stroke or likewise, because current services are directed at people with more severe strokes whose difficulties are more easily identifiable (Burns et al., 2018; Terrill, Schwartz, & Belagaje, 2018; Wolf et al., 2009). As a result, research into the efficacy of services that specifically target and provide for the mild stroke population remains minimal (Hodson, Gustafsson, Cornwell, & Love, 2017; Tellier & Rochette, 2009). Further developing an understanding of how people with mild stroke experience their transition from hospital to home, as well as health services, has the potential to inform the development of services that effectively meet their needs.

1.2 Thesis Aims

This thesis aims to explore the transition experience for people with mild stroke after they are discharged from an acute hospital stay. It is imbedded within a randomised controlled trial (RCT), which aimed to determine the efficacy of a new allied health-led, stroke specific self-management model of care for individuals with mild stroke discharged from acute hospital care in comparison to ‘standard care’. Consequently, this thesis also aims to explore people’s experiences of health services received under these two models of care. By exploring these aims, it is hoped that the essence of the mild stroke transition experience can be identified for people with mild stroke and their key support people (KSP). To achieve these aims, the thesis will be led by two key research questions:

- How do people with mild stroke and their key support persons experience their transition home from acute hospital care?
- How do people experience the MiStrEnGTH (Mild Stroke Enhancing and Guiding Transition Home) program in comparison to standard care?

1.3 Overview of Thesis

The thesis begins with a literature review in chapter 2, which discusses the definition of 'mild stroke' and its prevalence. The literature clearly identifies that the parameters that define mild stroke are still quite blurred and are yet to be solidified (Tellier & Rochette, 2009); however, it can be generally identified as a stroke that has less severe neurological sequelae and non-disabling functional deficits (Green & King, 2010; Kristensen, Postat, Poulsen, Jones, & Minet, 2014; Wolf, Barbee, & White, 2011; Wolf & Koster 2013). *The National Action Plan for Stroke* and *National Stroke Foundation Strategic Plan Update June 2015*, developed by the National Stroke Foundation of Australia (2013a; 2015a), identifies that people with stroke and their families experience particular concerns surrounding the return to home period, and the adjustment that is required during this time. As described in *Section 1.1*, this is referred to as the 'transition period' and in stroke research the first 6-months post hospital discharge is highlighted as particularly critical (Hall et al., 2012). People with mild stroke report changes in their cognitive capacity, energy levels, physical functioning, and emotional well-being during this period (Taule & Råheim, 2014). These changes within the person's functioning then impact on their daily activities and roles, especially in the areas of employment, home activities, leisure pursuits, driving and community mobility, and social interaction (Adamit et al., 2014; Taule & Råheim, 2014; Wolf, Brey, Baum, & Connor, 2012). The context of acute stroke care, however, does not allow for such issues to be addressed. Due to their limited observable difficulties, people with mild stroke often experience a short hospital length of stay, resulting in services focused on life-saving, acute interventions rather than rehabilitation, education and secondary prevention. Due to this, the literature review also involves an examination of the evidence-base for services that specifically provide for the mild stroke population after acute hospitalisation, highlighting current limitations. A final exploration of how health services for people with mild stroke may be altered to meet the needs of this population is then presented. This discussion draws on evidence and suggestions from the current knowledge base and develops recommendations for further practice and research. These recommendations are vital for changing services for people with mild stroke, to ensure that their needs are met and informs the basis of the research completed throughout this thesis.

Chapter 3 is a published scoping review that was completed in response to the identification of ongoing difficulties experienced by people with mild stroke highlighted within the literature

review chapter. The scoping review asks what services are available for people with mild stroke, and critically appraises the current evidence base. It identifies the literature available surrounding interventions that target person-centred secondary prevention and adaptation to newfound changes after mild stroke. In total, 12 articles were identified internationally that met these requirements, however only one of these articles was based on services conducted in the Southern Hemisphere, being located in New Zealand. It also highlighted the limitations identified within the current services researched, particularly that they focus on secondary prevention. The scoping review concludes with recommendations for future services for people with mild stroke and ways in which the evidence-base in this area may be improved. These recommendations state that services should expand the entire 'critical' transition period of 6 months post stroke and target complex, activity-level changes for people with mild stroke, taking into consideration their contextual and social factors. Furthermore, it foregrounds the need for qualitative research to enhance the knowledge held in this field. The results from this review informed the remaining sections and design of the thesis.

Chapter 4 outlines the methodology for the thesis. This thesis was guided by a tiered approach to IPA for PhD projects outlined by Smith and colleagues (2009). Included within this chapter is the author's research paradigm, process of participant recruitment and eligibility criteria, interventions studied in the thesis, data collection processes, methods to ensure methodological rigour and a reflexive section to portray the author's positioning. This chapter therefore clarifies how the research was conducted, ensuring a thorough understanding for the consequent results chapters.

Following the methodology chapter is the first of the results chapters in Chapter 5. This chapter explores the experience of a spousal dyad who received the MiStrEnGTH intervention during the first 9-months after a mild stroke. In this particular study, the participants are a male with mild stroke in his mid-sixties, and his wife. The chapter emphasises that even in theoretically the best of situations, issues and questions can remain long after a mild stroke. Furthermore, it highlights the contextual factors that might have made this spousal dyad's situation easier than others. The chapter has two major findings: 1) that there is a short period after a mild stroke that can be identified as the 'unexpected, undesirable and short-lived' where the person with mild stroke and their partner's lives change for a short period of time; and 2) that a 'new normal' can be observed after a mild stroke when people report life being similar to what it was before the stroke, but with small changes present and questions that remain. This chapter provides an in-depth, extended investigation of the mild stroke experience; however, as it only includes two individuals, the following chapters explore this experience from the perspective of multiple people.

Chapter 6 explores the 'essence' underlying the mild stroke experience, by exploring the phenomenon through five individuals' accounts over 6 months. The five people included in this

study were of varying ages, genders, marital and socio-economic statuses, and two received the MiStrEnGTH program. Whilst there were clear differences between each of the individuals in this study, there were three common factors that were observed which impacted each of their experiences. Two of these factors related to 'understandings and representation of stroke' and can be referred to as 'society defines the stroke experience' and 'the past determines the present'. An additional factor related to relationships and their impact on the mild stroke experience and can be referred to as 'underlying relationship dynamics revealed'. This chapter explores each of these factors and how they influenced participants' journeys in variable ways. The chapter then links these findings to the broader literature and how they can be used when working with people with mild stroke.

Chapter 7 then explores the same participants' experiences of stroke-related health services. Results from this chapter identify that for all people with stroke in this study, no matter the intervention they received, difficulty was observed during the diagnostic period. This difficulty appeared to stem from the ambiguous symptoms that participants presented with and both participants and healthcare professionals alike experienced difficulty in identifying mild strokes. The chapter then goes on to explore the differences in health service experiences, where participants appreciated a formal external support person, and identified that standard care services had numerous gaps but were still appreciated. This chapter, and the previous two, provide a thorough investigation of the mild stroke experience from the perspective of the person with mild stroke. However, as only chapter 5 explored the experience from the perspective of a single key support person, further investigation was needed from this viewpoint.

The final results chapter, chapter 8, discusses the 'essence' of key support person experiences after their partner had a mild stroke. All four participants in this study were aged in their sixties and seventies, and were female, resulting in a relatively homogenous sample. Three of the key support persons' husbands received MiStrEnGTH and one did not. Findings from this chapter demonstrate the impact that the mild stroke had on key support persons' personal time and how some were able to maintain their own meaningful activities, whilst others lost them, impacting on overall wellbeing. This phenomenon was identified as 'activities gained but time lost'. The other key finding in this chapter was the changes observed by the key support people in relation to their partners' emotions and behaviours which had differing levels of impact on relationships. This theme has been titled 'subtle changes but big impacts'.

Chapter 9 then brings the thesis together and discusses it as a whole, providing the main implications of the thesis's findings. Overall, the thesis has contributed to the mild stroke knowledge base by providing a broad understanding of the difficulties experienced by people with mild stroke during the transitional period following acute hospital discharge, including specific

limitations within services specifically designed for people with mild stroke. It has highlighted the impact of contextual influences on the ability of people with mild stroke to adapt to changes in their life. Unexpected findings from the thesis also contributed to the understanding of difficulties that may be occurring during the diagnostic period and why these might occur. This thesis has therefore laid the foundations for further work in the field and has provided direction for future research in the areas of interventions for people with mild stroke and diagnostic issues. Furthermore, it has provided suggestions for investigations from an economic perspective. Conclusively, mild stroke appears to be heavily influenced by a person's context, creates ongoing changes, and is yet to be fully addressed by hospital and health services.

Chapter 2: Literature Review

Chapter 1 provided an introduction to the thesis, including a brief rationale, the aims of the thesis, and an outline of the thesis structure. This chapter will extend upon details provided in chapter 1. It begins with a discussion around the definition of mild stroke. From there, the prevalence of mild stroke is presented, solidifying the importance of addressing the needs of this population. The transition period is then defined and discussed in order to contextualise the thesis and why certain timeframes were chosen for data collection. Following this, the difficulties experienced during the transition period that are currently identified in the mild stroke literature are presented. Mild stroke services are discussed, including acute management of stroke in Australia and service limitations for people with mild stroke. Possible avenues for addressing these limitations and meeting the needs of people with mild stroke are explored, such as self-management and consumer engagement. Consequently, this chapter provides the foundations and justification for the focus of the thesis.

2.1 Definition and Prevalence of Mild Stroke

A common thread of debate throughout the mild stroke knowledge base is the apparent lack of an agreed upon definition. The very term 'mild' is questioned by people that experience such a stroke, especially for those who experience greater changes as a consequence of stroke repercussions. With the prevalence of mild stroke increasing in society, reaching agreement on such a definition may become more important in order to strengthen the knowledge base surrounding it. Consequently, the following section aims to explore current discussions surrounding the definition of mild stroke and its prevalence.

2.1.1 Defining Mild Stroke

In a literature review by Tellier and Rochette (2009) it was identified that researchers are continuing to report differing definitions of mild stroke. One approach is to use tools that measure stroke severity, with certain score ranges classified as 'mild stroke' (Tellier & Rochette, 2009). Whilst this approach is effective in producing a concrete definition within studies, it is evident that between researchers, the use of these scores is inconsistent. The National Institute of Health Stroke Scale (NIHSS) has been one tool that has been repeatedly utilised due to its dominance in clinical application (Adams et al., 1999). Within this tool alone, variances between researchers have seen NIHSS scores of ≤6 to ≤8 used to identify mild stroke (Tellier & Rochette, 2009; Wolf et al., 2011). Other measures that have been used include the Orpington Prognostic Scale (OPS) with a score of <3.2, the Canadian Neurological Scale with a score of >8, and the Scandinavian Stroke Scale with a score of >49 (Tellier & Rochette, 2009). This variation in the definition of mild stroke through the utilisation of different measures, may be a result of context specific service circumstances and the availability of measures (Burchett, Umoquit, & Dobrow, 2011; Dobrow, Goel, Lemieux-Charles, & Black, 2006). For this reason, it can be argued that alternative methods of determining stroke severity may be utilised.

Another trend amongst stroke researchers is to employ descriptions of people with mild stroke to determine sample populations, alongside measures of stroke severity. Using this method, a mild stroke is often described as one that results in less severe neurological sequelae and non-disabling functional deficits (Green & King 2010; Kristensen et al., 2014; Wolf et al., 2011; Wolf & Koster, 2013) where major motor and speech impairments are not apparent (Wolf et al., 2011). Furthermore, researchers foreground that this population is often independent in activities of daily living and does not typically receive in-patient rehabilitation (Wolf et al., 2011). The Australian Institute of Health and Welfare (AIHW) (2013), has also attempted to define mild stroke, with the following description given:

'…the person needs no help and has no difficulty with any of the core activity tasks, but uses aids and equipment, cannot easily walk 200 metres, cannot walk up and down stairs without a handrail, cannot easily bend to pick up an object from the floor, cannot use public transport, can use public transport but needs help or supervision, needs no help or supervision but has difficulty using public transport.' (p.97)

This description provides clear evidence of the substantial variability in the classification of mild stroke, further blurring the definition. Further investigation is required to solidify a consistent definition. As the mild stroke specific evidence base gains more attention and more research is conducted in the field, clarifying this definition will become paramount in order to synthesise findings. However, from a clinical and lived experience perspective, it may be argued that each stroke should be given the same attention no matter how it is defined. For the purposes of this thesis, a mild stroke was defined by the treating stroke team and classified using a modified Rankin Scale score of 0 to 2.

2.1.2 Prevalence of Mild Stroke

Approximately fifteen million people worldwide experience a stroke each year (World Heart Federation, 2016). Within Australia, over 475,000 people are living with the effects of stroke and over 56,000 new and recurrent strokes occur each year, with a cost burden of an estimated five billion dollars (Deloitte Access Economics, 2013; 2017). Mild stroke contributes to approximately 35% of this population (National Stroke Foundation, 2015b). Furthermore, there is a trend towards people experiencing strokes at a younger age with milder impairments (O'Brien & Wolf, 2010; Wolf et al., 2009; 2011; Wolf & Koster, 2013). For instance, from a study sample of 7740 participants with stroke in the United States of America (USA), 45% were aged ≤65 years and 49.3% of the overall sample were deemed as having a mild stroke (Wolf et al., 2009). Whilst the rate and severity of stroke does vary between locations and races (Mendis, Puska, & Norrving, 2011), there is a trend towards increasing rates of stroke in younger adults with milder impairments. This distribution of people with mild stroke has consequently resulted in more people of working age experiencing and surviving a stroke, impacting on workforce productivity and increasing long term healthcare costs (Deloitte Access Economics, 2013; Wolf et al., 2009; Wolf & Koster, 2013). From this, it becomes clear that as more people continue to live with the effects of stroke for a longer period of time, it is vital that healthcare systems provide services that enhance independence and reduce reliance upon ongoing services.

2.2 The Transition Period

For people with mild stroke the transition period after acute hospital discharge, when they return to home and community life, is one of the most distinct and influential in their recovery (Hall et al., 2012). A transition, in general, is identified as the period following a triggering event that initiates a change in the way the person views themselves and their circumstances (Goodman et al., 2006; Hall et.al., 2012; Schlossberg, 1981). There are three types of transitions and these have been defined as anticipated, unanticipated and non-event transitions (Goodman et al., 2006; Schlossberg, 1981). Anticipated transitions are those that are predicted by the person and prepared for, such as marriage or the birth of a first child (Goodman et al., 2006). Alternatively, unanticipated changes are often rapid, and are not predicted by the individual, for example the occurrence of a health event (Goodman et al., 2006; Schlossberg, 1981). Finally, non-event transitions occur when an expected transition does not occur, for instance when a woman is unable to conceive a child (Goodman et al., 2006; Schlossberg, 1981). For people with mild stroke, the triggering stroke event represents an unanticipated transition and it is often rapid, resulting in immediate changes in the person's functioning that requires adaptation and adjustment (Glass & Maddox, 1992; Goodman et al., 2006; Schlossberg, 1981). It can result in the person needing to: alter their prior routines due to changes in functional and role capabilities, acknowledge ongoing changes, and build a new sense of self-identity (Glass & Maddox, 1992; Hall et al., 2012).

Research surrounding transitions that occur during adulthood has identified that the degree to which a transition impacts on an individual's life will be different for each person (Goodman et al., 2006). Often the impact will depend on how much the transition has changed the person's 'assumptive world', defined as the manner in which an individual views their situation and position in the world (Glass & Maddox, 1992; Goodman et al., 2006). There are three major elements that contribute to determining the extent of a transition and the effect it has on the person's assumptive world. The first of these is the individual's appraisal of the transition and their feelings toward it, also known as 'relativity' (Goodman et al., 2006). The second is the context in which the transition occurs, which relates to whether the event that caused the transition occurred to the individual or another in their life, impacting their perception of control (Goodman et al., 2006). Finally, the impact of changes during the transition contributes to its severity (Goodman et al., 2006). This includes the degree to which one's relationships, routines, and roles have been changed and the number of changes that have occurred (Goodman et al., 2006). Consequently, the person's assumptive world will continue to change through the transitional period as they become aware of more changes or are able to achieve new roles, altering the way they view themselves (Goodman et al., 2006). Much of this understanding around transitions is derived from Schlossberg's (1981)

work, where ‘A model for analysing human adaptation to transition’ was put forth, which predominantly drew on a life-course perspective.

The time it takes to move through a major transition, for instance serious health event or death of a loved one, can differ for each individual. An approximate time frame for major transitions, however, has been estimated at 2 months to 2 years (Goodman et al., 2006). The acquired brain injury (ABI) literature, however, identifies the ‘critical’ transitional and adaptation period as the first 6 months post hospital discharge for people who have experienced a brain injury, such as a mild stroke (Hall et al., 2012; Turner et al., 2007). It is this period that is the most essential to explore for people with mild stroke, as it is often the time in which their unique issues begin to emerge and spontaneous recovery starts to slow down. Health services should aim to assist the person with mild stroke to gain independence during this time, as well as enable them to adjust their assumptive world and develop an acceptance of their new circumstances and what is possible (Glass & Maddox, 1992). As further research about the transitional experience of people with mild stroke is developed, a picture of what the transition looks like can be formulated (Goodman et al., 2006). This information can then be utilised to further develop services that target the needs of people with mild stroke and can also provide this population with information that will help them to prepare for their transitional journey.

2.3 Implications of Mild Stroke

Whilst appearing mild in comparison to their moderate and severe counterparts, the implications of mild stroke can impact the daily lives of this population and often become chronic (Tellier & Rochette, 2009). The health status of people following a mild stroke is estimated to be below the 50th percentile of the general population, with only around ten per cent of all people with mild stroke recovering completely (Duncan et al., 1998; Tellier & Rochette, 2009). The effects of mild stroke have the potential to impact on all areas of a person’s life including their cognitive functioning, overall energy levels, emotional well-being, physical functioning and activities of daily living.

2.3.1 Person Level Changes

2.3.1.1 Cognition

Cognitive dysfunction is a common sequelae of mild stroke and is reported extensively in the literature. It is issues with cognition and perception that result in ‘hidden impairments’ in the mild stroke population and often become the most problematic (Gustafsson & Turpin, 2012). Wolf and colleagues (2011) reported in their cross-sectional study of people with mild stroke that 66% of their sample had at least one identified deficit in executive function. Similarly, 47.3% of participants in Jacquin and colleagues’ (2014) observational prospective cohort study were

identified as experiencing post-stroke cognitive impairment. Impairments associated with executive dysfunction include: reduced mental flexibility and cognitive processing limitations (Carlsson, Mölle,r & Blomstrand, 2004; Srikanth et al., 2003; Taule & Råheim, 2014), attention and concentration issues (Edwards, Hahn, Baum, & Dromerick, 2006; Green & King, 2007; Hommel et al., 2009; O'Brian & Wolf, 2010; Srikanth et al., 2003; Tellier & Rochette, 2009; Wolf et al., 2009), difficulties with organisation (Carlsson et al., 2004; O-Brien & Wolf, 2010; Wolf et al., 2009), and difficulties in decision making and structuring activities (Carlsson et al., 2004). Additionally, people with mild stroke have reported reduction in memory capabilities (Green & King, 2007; Tellier & Rochette, 2009), construction and spatial difficulties, and high-level language deficits (Srikanth et al., 2003). When a number of these sequelae are combined, it has been proposed that they present a syndrome, which has been given the name Astheno Emotional Syndrome (Carlsson et al., 2003; 2009). The following symptoms are said to comprise Astheno Emotional Syndrome: mental fatigability, memory difficulties, irritability, emotional instability, sensitivity to bright lights and loud sounds, stress sensitivity, and slower information processing (Carlsson et al., 2003; 2009). Evidently, whilst often hidden, the cognitive implications of a mild stroke are extensive and require specialised attention.

2.3.1.2 Fatigue

Fatigue is another common implication of mild stroke, as reported above in the description of Astheno Emotional Syndrome. For instance, Carlsson and colleagues (2003) reported 72% of a mild stroke sample experienced fatigue following the event. Likewise, in a study of employment following mild stroke by O'Brien and Wolf (2010), 58% of people who had returned to work after stroke experienced fatigue. Throughout the literature, people with mild stroke report concerns about their increased fatigue (Carlsson et al., 2004; Green & King, 2007; 2011; Gustafsson & Turpin, 2012; Hildebrand, Brewer, & Wolf, 2012; Kristensen et al., 2014, Taule & Råheim, 2014), lack of energy (Kristensen et al., 2014; Taule & Råheim, 2014; Tellier, Rochette, & Lefebvre, 2011), sleep disturbance (Green & King, 2007; Kim, Kim, Yang, Kim, & Kim, 2015; Taule & Råheim, 2014; Tellier et al., 2011) and reduced endurance (Green & King, 2011). For some people with mild stroke it appears that these experiences increase over time and become an ongoing issue (Kristensen et al., 2014). Issues with fatigue therefore have the potential to impact upon the daily lives of people with mild stroke, restricting their ability to participate in a range of meaningful activities.

2.3.1.3 Physical Functioning

A number of physical functioning changes occur following mild stroke and as these are often of a subtle nature, they are not always obvious during acute hospital assessment. People with mild

stroke report experiencing an 'unreliable body' (Taule & Råheim, 2014). This often results from changes in a wide range of physical functions, including: facial weakness, dysarthria and sensory loss (Edwards et al., 2006; Tellier & Rochette, 2009), pain and incontinence (Allen et al., 2002; Taule & Råheim, 2014), reduced mobility and fitness (Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007), deconditioning (Hildebrand et al., 2012), dizziness and difficulties with vision and swallowing (Allen et al., 2002), and decreased hand functioning (Wolf et al., 2012). Furthermore, Seymour and Wolf's (2014) study highlighted the implications that physical changes can have on people with mild stroke's sexual functioning, with mobility and hand functioning being identified as contributory causes. Consequently, physical limitations are important to identify following a mild stroke to ensure the impact on everyday life is limited.

2.3.1.4 Emotional Well-Being

Due to the number of changes that occur following a mild stroke, emotional well-being can be disrupted. Emotional disturbance tends to occur as individuals make comparisons between themselves and others, or with their pre-stroke self (Taule & Råheim, 2014). When they do this, it highlights areas of loss in their life, particularly emphasising things that are no longer attainable (Taule & Råheim, 2014). For instance, if people with mild stroke experience difficulty completing daily activities or are unable to complete tasks in the same manner as they did prior to their stroke they encounter psychological distress, such as feelings of embarrassment, insecurity, shame, stress, panic and fear (Carlsson et al., 2004; Green & King, 2007). Depression is another symptom that is reported frequently after mild stroke and in some cases, this can worsen over time (Allen et al., 2002; Carlsson et al., 2003; Green & King, 2007; 2010; Hildebrand et al., 2012; Husseini et al., 2012; Verbraak, Hoeksma, Lindeboom, & Kwa, 2012). Other emotional sequelae include: sadness, lack of joy, dissatisfaction (Taule & Råheim, 2014) loneliness (Green & King, 2007; Taule & Raheim, 2014), reduced self-expression, self-perception and self-esteem (Carlsson et al., 2004; Gustafsson & Turpin, 2012; Taule & Råheim, 2014), irritability (Edwards et al., 2006; Green & King, 2007; Hommel et al., 2008; Tellier et al., 2011), reduced life-satisfaction (Edwards et al., 2006), anger, frustration, and despair (Green & King, 2007), and decreased motivation (Hildebrand et al., 2012). People with mild stroke also experience an increase in concern about their health, and whilst this can be good, for many it extends beyond this and anxiety and worry can develop, especially in regards to experiencing another stroke (Carlsson et al., 2009; Kristensen et al., 2014; Rochette et al., 2007; Tellier et al., 2011). Overall, these emotional disturbances result in feelings of being out of control of their life and they struggle to regain order and structure (Carlsson et al., 2004). It must also be noted, however, that experiences of emotional well-being following mild stroke tend to differ between age groups with younger age groups being impacted to a greater extent

than older age groups (Wolf et al., 2012). In any case, a large number of changes appear to occur within the emotional functioning of the mild stroke population that warrant further investigation.

2.3.2 Daily Life Changes

The literature reports substantial changes in the daily lives of people with mild stroke. Often it is when they are attempting to re-engage with their daily lives that this population identifies mild stroke specific difficulties (Green & King, 2011). Following a mild stroke, people are forced to compromise between what they want to do and what they have to do as a result of functional limitations (Kristensen et al., 2014; Taule & Råheim, 2014), resulting in a change to the person's quality of life (Kristensen et al., 2014; Tellier & Rochette, 2009). Consequently, an occupational imbalance occurs as priorities shift towards completing essential activities instead of meaningful occupations (Kristensen et al., 2014). Specific areas that experience the greatest change following a mild stroke include: employment, home activities, leisure, driving and community mobility, and social interaction.

2.3.2.1 Employment

Due to the often younger age of people with mild stroke, work is one of the daily activities most often impacted by the stroke event. O'Brien and Wolf's (2010) study for instance, reported that 37% of participants with mild to moderate stroke never attempted to return to work, and a further 15% were unemployed 6 months after stroke. Of those that did return to work, 90% immediately returned to their previous job; however, 44% of this population were only able to complete their job at 75% of their previous ability and 12% performed at less than 75% of their previous ability (O'Brien & Wolf, 2010). Often this reduced performance ability is observable in the time it takes to complete tasks, with a longer period of time required due to a slower work pace (Gustafsson & Turpin, 2012; O'Brien & Wolf, 2010; Taule & Råheim, 2014; Wolf et al., 2009). These findings were reinforced in Green and King's (2007) study which identified that the experience of a stroke caused people to realign career goals, reduce work hours, change work type or retire early.

Decreased work performance can often be misunderstood by employers and colleagues due to the person's lack of observable physical deficits (Brey & Wolf, 2015; Gustafsson & Turpin, 2012). When workplaces or employees fail to identify the difficulties people with mild stroke experience in returning to work, negative interactions can occur. This can result in an overall damaging return to work experience (Carlsson et al., 2009; Gustafsson & Turpin, 2012). These kinds of interactions can produce feelings of failure in employment and a fear of not being able to manage work for a prolonged period (Taule & Råheim, 2014). Gustafsson and Turpin's (2012) case study of one woman's return to work experience was a particularly resounding exemplar. The case study highlighted the internal and external conflicts that occur during the return to work transition,

with issues surrounding disclosure of the event and the impact this might have, as well as an identity shift from a self-perceived 'productive' member of the team to one that is viewed negatively (Gustafsson & Turpin, 2012). As a result, the woman in this case tried to prioritise work over other occupations, leaving her with limited energy, increased fatigue and an overall low quality of life (Gustafsson & Turpin, 2012). Ultimately, this was not sustainable and resulted in the woman leaving the position and developing preconceived expectations, anxiety and reactions that altered her way of approaching future work situations (Gustafsson & Turpin, 2012). Whilst this study presented only one person's experience and is not a representation of every person's journey, it does demonstrate the impact that a negative return to work experience can have after mild stroke. Supporting people with mild stroke through this transition is therefore vital for them to be able to continue productive pursuits.

2.3.2.2 Home Activities

Findings are mixed in regards to participation in home activities for people with mild stroke. It appears that some people with mild stroke find the consequences of failing tasks within the home less threatening and are therefore more likely to complete activities in this environment in comparison to community environments (Taule & Råheim, 2014). Carlsson and colleagues (2004) observed that whilst people with mild stroke were able to complete activities within the home, the responsibility for completing, planning and organising the daily life of the home is often given to a spouse or, at times, children. Green and King (2007) identified similar results in their study, with more advanced activities, such as household management and banking, being associated with increased dependency. A difference in household participation was identified between age groups with older adults with mild stroke more likely to relinquish activities related to home maintenance in comparison to people of younger ages (Wolf et al., 2012).

2.3.2.3 Leisure Pursuits

Difficulties have been discussed in regards to participation in leisure for people with mild stroke. In a prospective cohort study by Adamit and colleagues (2015), 45.2% of participants experienced difficulty in leisure participation. Similarly, Hildebrand and colleagues (2012) reported a significant decline in high demand leisure activities for all participants in their study with between 24 and 47% of pre-stroke activities being relinquished. There also appears to be a difference in leisure participation amongst younger and older age groups with mild stroke (Wolf et al., 2012). Younger people with mild stroke tend to give up leisure and fitness activities such as bowling, bicycling, and camping, whereas older adults are more likely to maintain their leisure participation (Wolf et al., 2012). Furthermore, leisure pursuits that are intellectually demanding, such as reading, result in higher levels of strain for this population and therefore may be avoided (Carlsson et al., 2004). Other factors that contribute to a reduction in leisure participation include: a lack of time for

personal activities (Tellier et al., 2011), fatigue, mobility problems and environmental constraints (Rochette et al., 2007), and social reintegration issues and a lack of family support (Hildebrand et al., 2012). Participation in leisure has been strongly linked to well-being and satisfaction, therefore if participation levels are reduced in people with mild stroke it is quite likely that a person's perception of their well-being and overall life satisfaction will be affected (Rochette et al., 2007).

2.3.2.4 Driving and Community Mobility

It has become evident in the literature that community mobility and driving are of concern to people with mild stroke. Unlike leisure participation and household activities, all age groups report a reduction in this element of daily living, especially driving (Wolf et al., 2012). In this population, there is a proportion that do not return to driving and for those that do, they tend to make more errors than the general population (Carlsson et al., 2003; Hird et.al., 2015). In a study by Carlsson and colleagues (2003), 33% of participants from a sample of 75 that were driving prior to their stroke were not given permission to continue driving. Hird and colleagues (2015) further report that people with mild stroke who are able to return to driving demonstrate adequate ability in routine aspects of driving; however, errors are observed when complex and demanding elements of driving come into play. When people with mild stroke experience reduced participation or an inability to drive they report a loss of freedom (Rochette et al., 2007; Taule & Råheim, 2014), reliance on others, and a reduction in recreational pursuits (Rochette et al., 2007).

Community access and general transport has also been reported as an issue for people with mild stroke (Kristensen et al., 2014; Johansson, Mishina, Ivanov, & Björklund, 2007). In their prospective study, Edwards and colleagues (2006) reported that 45% of 219 participants experienced mobility issues. Adamit and colleagues (2014) further identified that trips out of town and mobility outside the home were particularly difficult for approximately a quarter of their mild stroke participants on self-rated measures. Overall, it appears that people with mild stroke are limited in their ability to participate in daily activities due to issues with driving and community access.

2.3.2.5 Social Interaction

Issues with social functioning have also been associated with mild stroke. In a prospective cohort study by Hommel and colleagues (2009), 66.1% of 84 participants with mild to moderate stroke were identified as experiencing significant social functioning issues, with 26.8% and 39.3% experiencing moderate and severe impairment in social functioning respectively. Within this study social dysfunction was identified to continue months following the stroke, placing particular burden on younger survivors (Hommel et al., 2009). Social functioning can be further broken down into

social interactions and relationships that take place within the family and those that occur with others outside the family unit.

A mild stroke presents a number of changes to both the individual and their family which can impact on relationships. The consequences of stroke can force a change in daily routines within the home and role changes between the person with mild stroke and their spouse, causing heightened stress (Carlsson et al., 2004; Green & King, 2010; Tellier et al., 2011). Furthermore, the person with mild stroke often becomes dependent on family members, altering the structure and dynamics of relationships (Taule & Råheim, 2014; Tellier et al., 2011). With the added stress to relationships following a mild stroke, some reports have identified that marital functioning scores worsen over time reaching a dysfunctional level in some cases (Green & King; 2010; 2011) and the risk of divorce increases (Carlsson et al., 2004). Relationships with other members of the family are also altered following the stroke. A restriction in the ability to meet the needs of their family members and those that once depended on them has been reported by people with mild stroke, which can impact on their mood and emotions (Carlsson et al., 2004; Green & King, 2007). Ultimately, this population require help, patience and support from their family (Carlsson et al., 2004); however, this can be difficult given the life changes that their family are also experiencing.

Outside the family unit, people with mild stroke report a number of difficulties in regards to social interaction and an overall reduction in social activities (Carlsson et al., 2004; Green & King, 2007). In a prospective study by Edwards and colleagues (2006), 36% of 219 participants reported reduced participation in social activities. This reduction in social participation may result from experiences and feelings associated with social participation for this population. For instance, people with mild stroke have reported experiencing a stigma in regards to how people view them, stating that they often feel that they are seen as someone who has had a stroke, rather than as an individual (Rochette et al., 2007). Furthermore, a lack of confidence (Taule & Råheim, 2014), feelings of isolation (Green and King, 2007; Taule & Råheim, 2014), feelings of being watched and evaluated (Carlsson et al., 2004) and unrealistic expectations from others (Carlsson et al., 2004) have also been reported. Hidden deficits can also make it hard for the general community to understand difficulties experienced by people with mild stroke, causing frustration for the person with mild stroke (Taule & Råheim, 2014). All of these factors can consequently result in participation in society becoming unpleasant and tedious for people with mild stroke (Taule & Råheim, 2014).

2.4 Mild Stroke Services

It is apparent that a number of difficulties occur for people with mild stroke post hospital discharge, indicating the need to investigate services that provide for this population. The following section

will explore current acute and post-acute services for people with mild stroke and identify areas for growth.

2.4.1 Acute Management of Stroke in Australia

The acute treatment of stroke is relatively uniform across all stroke severities, with some differentiation in service treatment according to diagnosis. The *Acute Stroke Clinical Care Standards 2015* of Australia provide a clear set of standards for the management of acute stroke (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2015), see Table 2.1. The first three standards outline the assessment, hyper-acute and stroke unit requirements for Australian stroke care services. Of note, is the emphasis on the utilisation of, and admission to a stroke unit which has been endorsed internationally (Holland, 2000; Kalra, Wolfe, & Rudd, 2011; National Stroke Foundation, 2015c).

Table 2.1: Acute Stroke Clinical Care Standards 2015 (ACSQHC, 2015)

Standard	**Important Elements of Standard**
1. A person with suspected stroke is immediately assessed at first contact using a validated stroke screening tool, such as the F.A.S.T. (Face, Arm, Speech & Time) test.	• Clinicians are to assess all people with suspected stroke using a validated screening tool.
2. A patient with ischaemic stroke for whom reperfusion treatment is clinically appropriate, is offered reperfusion treatment in accordance with settings and time frames recommended in the *Clinical guidelines for stroke management*.	• Imaging is to be urgently organised for patients with suspected stroke. • People with ischaemic stroke are recommended to receive reperfusion treatment where it is clinically indicated and if it corresponds with the patient's preferences. • For people with haemorrhagic stroke, time-critical therapies are recommended, for instance blood pressure control.
3. A patient with stroke is offered treatment in a stroke unit as defined in the *Acute stroke services framework.*	Definition of a Stroke Unit: • Co-located beds within a geographically defined unit. • Specialised inter-professional team with medical, nursing and allied health professionals. • Inter-professional team that meets at least once per week.

	• Regular programs of staff education and training related to stroke. (National Stroke Foundation, 2015c)
4. A patient's rehabilitation needs and goals are assessed, by staff trained in rehabilitation, within 24-48 hours of arrival in the stroke unit. Rehabilitation is started as soon as possible, depending on the patient's clinical condition and preferences.	• Assessment of rehabilitation needs and goals needs to be completed using a validated tool. • Rehabilitation should be started in the acute phase of care. • Each member of the multidisciplinary team (MDT) (including medical, nursing, physiotherapy, speech therapy and occupational therapy staff) are to complete their part of the assessment, either as a team during a MDT meeting or as part of a ward round.
5. A patient with stroke, while in hospital, starts treatment and education to reduce their risk of another stroke.	• Clinicians are to assess, treat and educate patients about their risk of another stroke. • Discussion, provision of written information and prescription of medications should be incorporated. • Interventions that are time-limited, such as carotid endarterectomy, may also be included.
6. A carer of a patient with stroke is given practical training and support to enable them to provide care, support and assistance to the person with stroke.	• Clinicians are to offer carers education on stroke and information to support the carer's own well-being. • Clinicians should also provide practical carer training and contact details of support services. • Training and support should be completed before the patient leaves the hospital.
7. Before a patient with stroke leaves hospital, they are involved in the development of an individualised care plan that describes the ongoing care that the patient will require after they leave hospital.	• Clinicians can use tools such as *My stroke care plan* to develop the patient's care plan. • The plan must include: rehabilitation goals, initiatives to manage risk factors (e.g. lifestyle modifications and medicines), equipment needs, follow-up appointments and contact details for ongoing support services. • Plan is to be provided in writing to the patient, before hospital discharge. • Copy of plan is to be given to the patient's general practitioner/ongoing clinical provider within 48 hours of discharge.

	• The care plan is separate to a clinical discharge summary.

It is proposed that the last four standards may be the most difficult for clinicians to meet for people with mild stroke, given their limited length of stay in hospital. The average length of stay (LOS) for all stroke hospitalisations in Australia has been identified as 9 days, with a range of 3.4-9.6 days (AIWH, 2013). As severity was not distinguished in the identification of LOS in the AIWH's report, it is difficult to determine the exact LOS of people with mild stroke; however, it is noted that the average for people with a transient ischaemic attack (TIA) is 3.4 days (AIWH, 2013). Due to the minimal observable deficits of people with mild stroke they are more likely to be discharged at a rate that is similar to people with TIA. This short LOS can lead to the focus of care being aimed at life-saving and acute, morbidity-reducing interventions, such as reperfusion, leaving limited time for rehabilitative therapies. Moreover, even if their hospital LOS is longer than this average, people with mild stroke's rehabilitative needs may be hard to identify outside the context of complex activities. This issue has been supported in the wider literature where it has been identified that short hospital stays can inhibit the ability of health professionals to make in-hospital visits to educate patients on vital elements of post-discharge life, such as community reintegration, counselling and problem solving (Tellier & Rochette, 2009), post-discharge self-care (Sides et al., 2009), and risk factors and medications (Sides et al., 2012; Tellier & Rochette, 2009). The difficulties observed in meeting these requirements were outlined in the Stroke Foundation's *National Stroke Audit – Acute Services Report* (2017), where it was reported that 33% of people with stroke were not assessed by a physiotherapist within 24-48 hours of admission, 14% did not participate in rehabilitation therapy within 48 hours of initial assessment, 10% did not commence treatment for a rehabilitation goal during their acute admission, 35% were not given a written care plan when discharged from acute care, 38% of carers were not assessed in regards to their support needs, and 43% of carers were not provided with training. Overall, it can be observed that there are some limitations within acute stroke services in Australia, and attention should be directed towards determining how to maximise service provision given the reduced length of stay.

2.4.2 Service Limitations for People with Mild Stroke

On an international level, concern exists in regards to the level of service provision for people with mild stroke. As outlined above, people with mild stroke often spend a short period of time in hospital and when discharged, a large proportion receive no further rehabilitation services (Carlsson et al., 2009; Edwards et al., 2006; Green & King, 2010; 2011; Kristensen et al., 2014; Wolf, et al., 2009; 2011; Wolf & Rognstad, 2013). Furthermore, participants with mild stroke in some studies

have stated that: they were discharged too early, they were not immediately admitted to hospital in the first place or that healthcare professionals experienced difficulty in providing an accurate diagnosis (Carlsson et al., 2009). These identified difficulties appear to have occurred within health services that are underpinned by general stroke service frameworks.

When people with mild stroke do receive services, including those within the hospital, the services often do not meet all their needs. Particular areas that people with mild stroke have identified as being inadequately addressed include caregiver and family education (Green & King, 2007; 2010; Hillsdon, Kersten & Kirk, 2013), information provision surrounding prognosis and symptoms (Carlsson et al., 2009; Green & King, 2007; Taule & Råheim, 2014), return to work (Gustafsson & Turpin, 2012; O'Brien & Wolf, 2010; Wolf et al., 2009), community integration (Wolf et al., 2009), family and marital relationship functioning (Green & King, 2007; Wolf et al., 2009), sexual functioning (Seymour & Wolf, 2014), driving (Rochette et al., 2007; Wolf et al., 2009), fatigue (Verbraak et al., 2012) and mood imbalances (Husseini et al., 2012; Verbraak et al., 2012). This revelation is somewhat worrisome given that many of the elements listed require optimal functioning for participation in everyday life.

The inability of acute hospital services to detect difficulties experienced by the mild stroke population may contribute to the unmet needs outlined above (Green & King, 2010; O'Brien & Wolf, 2010; Tellier & Rochette, 2009; Wolf et al., 2009; Wolf & Koster, 2013). The difficulties that have been identified by people with mild stroke are often experienced in the context of complex occupations, such as driving and work, and therefore without observing these activities within a 'real world' setting, limitations such as executive dysfunction may go unnoticed (Kristensen et al., 2014; Gustafsson & Turpin, 2012; O'Brien & Wolf, 2010; Wolf et al., 2009). Furthermore, there is a tendency for healthcare professionals to focus on function, outcome and rehabilitation rather than how the person with stroke experiences the impact of their stroke on a daily basis (Taule & Råheim, 2014). Consequently, this leads to differing priorities between the health professional and person with stroke. Additionally, a lack of established care models has also been identified as contributing to the issue of service limitations for people with mild stroke (Allen et al., 2002). Without such models, it can be hard for health professionals to determine the most comprehensive assessment and follow-up procedure for this population (Allen et al., 2002).

As a result of the difficulties observed for providing services to people with mild stroke within general stroke service frameworks, mild stroke specific services have started to be developed. To thoroughly investigate the efficacy of mild stroke specific services reported in the literature, a scoping review was completed by the research team, please see *Chapter 3.*

2.5 Meeting the Needs of People with Mild Stroke

A number of recommendations for improving mild stroke services have been made throughout the literature. One of the biggest findings from the evidence base is that a shift in focus needs to be made. Currently, recovery is at the forefront of research and service provision for people with mild stroke but given the specific changes that occur for people with mild stroke it may be more appropriate to focus on adjustment and adaptation (Bandura, 2001; Taule & Råheim, 2014). This change has been supported by stroke researchers who have promoted the initiative to move towards assisting people to cope with loss and adaptation to changes in their life, in order to help them move from their former identity to one that is positive after stroke (Bhogal, Teasell, Foley, & Speechley, 2003). This essentially enables an individual to develop a sense of mastery despite any deficits that remain post stroke (Glass & Maddox, 1992). Notably, it must be ensured that a balance be maintained whilst doing this in regards to supporting the person's hope and their aspirations whilst being realistic regarding the changes that may be ongoing (Jones, Livingstone, & Hawkes, 2013). This approach therefore enables a long-term perspective to be considered for people with mild stroke who may live indefinitely with certain changes (Carlsson et al., 2009). Whilst focusing on this adaptation to change, the elements of stroke services that are currently lacking (see section 2.4.2), should also be considered and incorporated into new models of care. Self-management is a particular method that may be able to meet the requirements outlined above in regards to the provision of mild stroke services.

2.5.1 Self-Management

Self-management is gaining support within the stroke field, with positive findings observed in its provision (Lennon, McKenna, & Jones, 2013). The American Occupational Therapy Association (2015, p.1) defines self-management as a strategy that 'is about being in charge of one's life and managing one's condition, instead of being managed by the condition'. The concept of self-management is quite broad and includes elements such as enhancing knowledge, setting goals, decision-making, and the use of health-protective behaviours (Jones et al., 2013). At the basis of this approach lie the concepts of knowledge and behaviour change, which incorporate a certain level of self-responsibility (Jones et al., 2013). It utilises Social Cognitive Theory and the understanding that personal goals, actions and commitment are influenced by self-efficacy and enhanced through strategies that promote goal setting and problem solving (Bandura, 2001; Jones et al., 2013). Self-efficacy is particularly important in this approach, as an individual's view of themselves will determine the goals they set, the effort they put into achieving those goals, and the likelihood they will maintain a change for the better (Bandura, 2001). This approach may be

particularly suited to people with mild stroke due to the higher level of functioning that this population demonstrates (Hildebrand et al., 2012).

Within the stroke literature a number of benefits to the utilisation of self-management have been noted. The use of self-management for chronic symptoms has been suggested as being able to support work performance by enhancing a sense of autonomy and self-sufficiency (O'Brien & Wolf, 2010; Wolf et al., 2009). Other benefits observed include improvements in: confidence in recovery, fine motor ability, stroke knowledge, physical ability, social support (Lennon et al., 2013), self-efficacy, family and role functioning, (Bandura, 2001; Lennon et al., 2013), pain and distress, cognitive symptom management, quality of life and use of medical services (Bandura, 2001). Furthermore, whilst reducing health risk factors and enhancing quality of life, self-management has also been demonstrated to be cost effective and well received by participants (Bandura, 2001). The fact that many self-management programs are home-based ensures that cost is reduced through eliminating the need to purchase special equipment or facilities (Bandura, 2001). Further, the individualisation and provision of personal guidance and informative feedback has been appreciated by people that have utilised self-management programs (Bandura, 2001).

With this in mind, the RCT in which this study was imbedded aimed to provide a stroke specific self-management program (SSMP) for people with mild stroke and examine its efficacy in comparison to standard care in terms of quality of life, client mood and confidence, and level of function. The SSMP aimed to assist people with mild stroke to manage their symptoms, physical and psychosocial consequences, rehabilitation needs and improve their lifestyle. The program was tailored to each person's needs, with sessions following a set-format that promoted the development of self-efficacy.

2.5.2 Methods of Service Provision for Self-Management

Self-management may be provided through a multitude of avenues, however questions surrounding the best mode of delivery still remain (Lennon et al., 2013). The use of technologies has been suggested to improve the accessibility of interventions (Jones et al., 2013). Telephone use is one technology that has been identified as successful in targeting people of a large geographic area and assisting people with mild stroke to have questions answered after return home (Sides et al., 2012). Telephone communication is also a convenient, relatively inexpensive, and less resource intensive method of providing services (Sides et al., 2012). Furthermore, research into telehealth has demonstrated that it is met with acceptance by people with mild stroke and is valued to the same degree as face-to-face treatment (Lai, Woo, Hui, & Chan, 2004). Other avenues that have been utilised to deliver self-management programs include: DVDs, case vignettes, exercise sessions, problem solving quizzes, videoconferencing, workbooks (Lennon et al., 2013) and computer

assisted implementation (Bandura, 2001). In any circumstance, the method used must promote an environment where a strong relationship of trust, mutual respect, shared decision making and good communication can be harboured between the health professional and person with mild stroke (Jones et al., 2013). Given the above findings regarding the acceptance of telehealth by people with mild stroke, telephone calls were used for the provision of the SSMP in the RCT in which this study was imbedded.

The optimal timing of self-management models has also been identified as an area of developing knowledge (Lennon et al., 2013). Previous findings have suggested that the timing of self-management programs should optimally occur after the acute period as this ensures people are over the initial 'shock' of experiencing a stroke and may also have experienced changes within their home life (Jones et al., 2013). Furthermore, any type of informational support given must ensure that the person is able to process information appropriately and have the capacity to make informed decisions (Glass & Maddox, 1992). The concept of incorporating multiple sessions into self-management programs has also been supported (Goodman et al., 2006; Sit, Yip, Ko, Gun & Lee., 2007), as this enables programs to support the person as their situation changes throughout their transitional trajectory and address specific concerns as they arise for the individual (Glass & Maddox, 1992; Goodman et al., 2006; Jones et al., 2013). For this reason, self-management should be viewed more as a process than as a structured program (Jones et al., 2013). The SSMP studied the RCT in which the current study was imbedded, consequently provided the program throughout the first 6 months after acute hospital discharge. In total five sessions were offered, with the first three being provided at 1-, 4- and 8- weeks post-acute hospital discharge, and the last two at a time point that was mutually agreed upon by the allied health professional providing the program, the person with stroke, and/or their key support person.

2.5.3 Consumer Engagement

Self-management presents a potential solution to providing comprehensive, targeted services to people with mild stroke, however it is essential that consumers are included in the development and evaluation of services in order to ensure that they are truly appropriate (National Stroke Foundation, 2015d). The Stroke Foundation of Australia has identified consumer engagement as a core strategic priority, stating that the inclusion of consumers strengthens advocacy and decision making in regards to research, through increased contact with, and improved understanding of people with stroke (National Stroke Foundation, 2013b; 2015a). One way that researchers can strive to include consumers in the development and evaluation of services is through qualitative research. Qualitative research aims to understand the 'what', 'how' or 'why' of research questions in healthcare (Green & Thorogood, 2004). Furthermore, it has been identified as crucial in facilitating change at a

systemic level due to its ability to describe what is important to the people that receive services and their carers (Al-Busaidi, 2008; Taylor & Francis, 2013). For instance, at a policy level qualitative research has the ability to provide evidence for population need and indicate potential solutions for problems by voicing the concerns of individuals with particular health concerns (Green & Thorogood, 2004). Components of health services such as patient satisfaction and explanation of attitudes that are unable to be holistically explored in quantitative research are also able to be investigated using qualitative methods (Al-Busaidi. 2008). Historically however, qualitative research has been limited in health service research, with randomised controlled trials being the favoured approach (Hoff & Witt, 2000; Taylor & Francis, 2013). Consumer engagement is vital to service development and evaluation, therefore as mild stroke services continue to be developed and researched it is important to incorporate qualitative measures. As a result, this thesis uses a qualitative approach to investigate the services provided in the RCT in which it is imbedded, as well as the overall transitional experiences of people with mild stroke.

2.6 Summary

This literature review has aimed to identify the current knowledge base surrounding mild stroke, its implications and the services available for this population. It is evident that the knowledge base surrounding mild stroke is still developing with a number of areas for further development identified. The ambiguity surrounding the definition of mild stroke is an initial indicator of the need for research in this field. As it has been observed that the prevalence of people experiencing mild strokes is increasing, it is essential that this ambiguity is met with clarification in order to develop a rigorous evidence base. It appears that the transition period from hospital discharge to home is one of particular importance to people with mild stroke, and one that should be supported by health services to ensure that this population is able to adjust and adapt to changes in their lives and maintain independence. Within this transition period, people with mild stroke experience a number of difficulties in the areas of cognition, fatigue, physical functioning and emotional well-being. These then impact on the person's ability to participate in daily activities, such as employment, household activities, leisure pursuits, community mobility and social interaction. As a result of short hospital stays, the ability of health services to target such difficulties is limited. Furthermore, current services that are offered for people with mild stroke, either are not mild stroke specific or are unable to holistically meet the needs of people with mild stroke. In order to ensure that this gap is met, this literature review has identified suggestions for future services and research. Firstly, a shift of focus to one that assists people to adjust to chronic changes, rather than one that focuses solely on rehabilitation is advised. Secondly, self-management as a way to help this adjustment has been identified as a possible low cost, effective approach that requires further investigation. Lastly,

the utilisation of consumer engagement in research into possible services has been recognised as vital to ensure that services are truly meeting the needs of this population. In conclusion, the mild stroke population is one that requires further investigation, especially in regards to services that cater for the adjustments that this population is required to make.

Chapter 3: Scoping Review

Reference: Hodson, T., Gustafsson, L., Cornwell, P., & Love, A. (2017). Post-acute hospital healthcare services for people with mild stroke: a scoping review. *Topics in Stroke Rehabilitation, 24*(4): 288-298. doi: 10.1080/10749357.2016.1267831

The first chapters of this thesis laid the foundations for the research topic and why people with mild stroke require services targeted to their needs, and the importance of exploring transitional experiences through qualitative means. This next chapter extends upon this and highlights the gaps in services for people with mild stroke through a scoping review of the available literature. The scoping review focuses on services provided after acute hospital discharge, that address person-centred secondary prevention, and adaptation to newfound changes. It also includes a critical appraisal of the literature in order to determine which areas of research in this field require improvement.

This scoping review was published in *Topics of Stroke Rehabilitation* in 2017. The chapter consists of the pre-publication manuscript, however outcomes of an updated search have been included in the chapter summary. The chapter has been formatted to comply with APA guidelines.

Contributor	**Statement of contribution**
Tenelle Hodson (candidate)	Conceptualisation of research design and question (60%) Conducting literature search (90%) Reviewing of articles (70%) Critical appraisal of articles (40%) Writing and editing of manuscript (70%) Response to reviewers and revision (75%)
Louise Gustafsson	Conceptualisation of research design and question (20%) Conducting literature search (5%) Reviewing of articles (15%) Critical appraisal of articles (10%) Writing and editing of manuscript (15%) Response to reviewers and revision (10%)
Petrea Cornwell	Conceptualisation of research design and question (20%) Conducting literature search (5%) Reviewing of articles (15%) Critical appraisal of articles (10%) Writing and editing of manuscript (10%)

	Response to reviewers and revision (10%)
Amanda Love	Conceptualisation of research design and question (0%) Conducting literature search (0%) Review or articles (0%) Critical appraisal of articles (40%) Writing and editing of manuscript (5%) Response to reviewers and revision (5%)

Post-acute hospital healthcare services for people with mild stroke: a scoping review

3.1 Abstract

Background: People with mild stroke contribute significantly to the overall stroke population. Previously this population has been viewed as having limited impairments, receiving minimal services following hospital discharge. Recent findings demonstrate that the implications of mild-stroke are more significant than originally comprehended and further services are warranted.

Objectives: To identify the evidence-base regarding services for people with mild stroke, post-acute hospital discharge, that target secondary prevention and/or changes following stroke.

Methods: Scoping review utilising the five-stage framework proposed by Arksey and O'Malley, with additional revisions by Levac, Colquhuon and O'Brien. A critical appraisal using the *Downs and Black Checklist* was added to determine methodological quality of studies. The search strategy used six databases: Pubmed, Embase, PsycINFO, CINAHL, OTseeker, and Scopus, alongside a hand search. Three researchers were involved in article selection and two in critical appraisal.

Results: Twelve articles met inclusion criteria from 589 identified. A number of study methodologies were used to assess services, with varying methodological qualities. Studies were located within two major regions in the world. Five main approaches to service provision were identified: telehealth, exercise and education, comprehensive cardiac rehabilitation, one-off visits and care-plan development, and community group programs. The majority of programs focussed on secondary prevention and were aimed at an impairment level, with a mix of findings observed.

Conclusion: Further development and assessment of services is warranted. Incorporation of the entire transition period, and research that is specific to mild stroke and location is advised. Attention to maximising participation in daily life, secondary prevention, emotional well-being and careful reporting is needed.

3.2 Introduction

Stroke is one of the biggest contributors to death and disability worldwide (World Heart Federation, 2016). Studies investigating the prevalence of stroke have identified that a third (National Stroke Foundation, 2015b) to almost half (Wolf et al., 2009) of people with stroke experience a 'mild' stroke. Mild stroke is defined by a National Institute of Health Stroke Scale (Adams et al. 1999) score of ≤6 (Wolf et al., 2011). People with mild stroke often do not exhibit major motor or speech impairments and are frequently able to independently complete activities of daily living (Wolf et al., 2011). For this reason they are perceived to lack impairment and are quickly discharged after a short hospital stay, with a large majority not accessing any further health services (National Stroke Foundation, 2015b). Recent evidence suggests that the implications of mild stroke may be extensive, however there is limited research into services that cater for this population (Tellier & Rochette, 2009). This scoping review aims to explore the current evidence-base regarding post-acute hospital discharge services for people with mild stroke and identify any gaps that may exist.

Over the last ten years interest in the mild stroke population has started to gain emphasis amongst researchers. This has developed from the identification that difficulties appear to impact people with mild stroke on a daily basis and full recovery does not occur for a substantial proportion of this population (Edwards et al., 2006). Many difficulties stem from changed cognition post stroke, and these often remain undetected and can become chronic (Adamit et al., 2015; Carlsson et al., 2009; Jacquin et al., 2014; Srikanth et al., 2003; Wolf et al., 2011; Wolf & Rognstad, 2013). Presenting areas of difficulty include attention and concentration (Edwards et al., 2006; Green & King,2007; O'Brien & Wolf, 2010; Tellier & Rochette, 2009), organization and planning (Carlsson et al., 2004; O'Brien & Wolf, 2010), memory (Green & King, 2007; Tellier & Rochette, 2009), decision-making and information processing (Carlsson et al., 2004). Moreover, fatigue and sleep disturbance are commonplace and can increase over time (Carlsson et al., 2003; Flinn & Stube, 2010; Green & King, 2007; Hildebrand et al., 2012; Kim et al., 2015; Kristensen et al., 2014; O'Brien & Wolf, 2010; Tellier & Rochette, 2009). Changes in executive functioning and issues with fatigue are reported extensively throughout the literature, however, it is the effect these have on daily life activities that make them most troublesome.

Work (Edwards et al., 2006; Flinn & Stube, 2010; O'Brien & Wolf, 2010) social participation (Edwards et al., 2006; Flinn & Stube, 2010), driving and community mobility (Edwards et al., 2006; Flinn & Stube, 2010) are impacted by cognitive difficulties and fatigue. The often younger age of people with mild stroke, in comparison to the rest of the stroke population (Wolf et al., 2009), places employment as an area that experiences the most change. A significant number of people with mild stroke are unable to return to work, or return to work at a different

capacity (Carlsson et al., 2003, 2009; Edwards et al., 2006; Green & King, 2007, 2011; Johansson et al., 2007; Kristensen et al., 2014). For those who are able to return to work, they are presented with a number of issues including: fear of work sustainability (Brey & Wolf, 2015), feelings of failure and not belonging, and a lack of support (Taule & Råheim, 2014). In regards to social participation, a decreased interest and participation in social activities and interpersonal relationships is reported (Edwards et al., 2006; Green & King, 2007; Hommel et al., 2009; Rochette et al., 2007). This can be observed in marital relationships where the risk of divorce increases following stroke (Carlsson et al., 2004; Green & King, 2007). The impact of mild stroke on community mobility is identifiable through those that are unable to return to driving, and the number of errors that are made by those that do (Carlsson et al., 2003,2009; Hird et al., 2015; Rochette et al., 2007). Additionally, those that do not return to driving report difficulties with accessing transport (Edwards et al., 2006; Johansson et al., 2007; Kristensen et al., 2014; Rochette et al., 2007; Taule & Råheim, 2014). Whilst these areas predominate, the literature also demonstrates a substantial reduction in leisure pursuits and an increased dependency during household activities (Carlsson et al., 2004,2009; Green & King, 2007; Hildebrand et al., 2012; Rochette et al., 2007).

Changes that occur in areas of daily life can alter a person with mild stroke's emotional wellbeing. For instance, the inability to work or work at full pre-stroke capacity can result in a diminished sense of life satisfaction, well-being, self-worth and social identity (Gustafsson & Turpin, 2012; Wolf et al., 2009). Furthermore, if people are forced into changing their career goals they may experience emotions such as anger, depression and frustration (Green & King, 2007). Other emotional sequelae that are exhibited by this population include: a diminished sense of self (Taule & Råheim, 2014), feelings of uncertainty (Carlsson et al., 2009; Kristensen et al., 2014), anxiety and worry (Carlsson et al., 2004; Johansson et al., 2007; Kristensen et al., 2014; Verbraak et al., 2012), irritable mood (Edwards et al., 2006; Green & King, 2007; Hommel et al., 2009), and emotional instability (Carlsson et al., 2004; Green & King, 2007). The high prevalence of emotional sequelae experienced highlights the significance that a mild stroke event can have on an individual and that they require further support.

Whilst the impact of mild stroke is evidently significant, the services that provide for this population and evidence supporting appropriate interventions is lacking. Studies have identified that a large portion of people with mild stroke receive minimal to no services following acute hospital care (Carlsson et al., 2009; Edwards et al., 2006; Green & King, 2011; Wolf et al., 2009; 2011; 2013; Tellier et al., 2011). Intimacy (Seymour & Wolf, 2014), expectations for future health improvement (Taule & Råheim, 2014), driving (Rochette et al., 2007; Wolf et al., 2009), personal

relationships, work, and community participation (Wolf et al., 2009) are particularly inadequately addressed, leading to feelings of being unprepared (Carlsson et al., 2009). It is necessary to improve the state of services available for people with mild stroke and to do this, current services must be identified and discussed. As a result, the following research question was developed, 'What is the evidence-base surrounding interventions and services that target person-centred secondary prevention and adaptation to newfound changes, post hospital discharge.'

3.3 Methodology

This scoping review utilised the methodology outlined by Arksey and O'Malley (2005), with additional revisions from Levac, Colquhuon and O'Brien (2010). The steps were: (1) Identification of the Research Question, (2) Identification of Relevant Studies, (3) Study Selection, (4) Charting of the Data, and (5) Collating, Summarizing and Reporting (Arksey & O'Malley, 2005). The optional step proposed by Levac and colleagues (2010) of 'Consultation', was not undertaken due to feasibility. A critical appraisal, however, was introduced to improve methodological quality and enable discussion of research quality. The critical appraisal was completed by two members of the research team using the *Downs and Black Checklist* (Downs & Black, 1998), with articles rated separately and scores discussed until consensus was reached. The *Downs and Black Checklist* assesses the methodological quality of both randomised and non-randomised controlled trials, and is especially useful for studies of health interventions (Downs & Black, 1998). The checklist has been proven to have high internal consistency, good test-retest and inter-reliability and good face and criterion validity based on the Quality Index (Downs & Black, 1998).

3.3.1 Data Sources and Search Strategy

A specialist School of Health and Rehabilitation Sciences librarian revised the search strategies and terminologies to ensure they aligned with the research question. The search used the following databases: Pubmed, Embase, PsycINFO, CINAHL, OTseeker and Scopus. Search terms used were "mild stroke" OR "minor stroke" OR "non-disabling stroke" AND "services" for the former five databases. Scopus was accessed last and the titles of articles found in the initial search were entered into this database for further identification of articles. No restriction was placed on years for inclusion as it was anticipated that the search would yield limited results. In addition to the database search, articles were found through hand searching of reference lists. In cases where only the abstract could be identified, the related journal was contacted to determine whether further research had been published.

3.3.2 Eligibility Criteria

To be included the article needed to discuss interventions and services that: (1) related to person-centred secondary prevention or assisted with the adaptation to post mild stroke changes, and (2)

were administered post hospital discharge. Flexibility was given to studies that included people with transient ischemic attack (TIA). Studies were excluded if they: (1) did not have a component specifically designed for people with mild stroke, (2) did not have outcomes related to person-centred secondary prevention, (3) focussed solely on the physical impact of mild stroke and (4) were a protocol. For further detailed information regarding eligibility criteria see Appendix 1.

3.3.3 Procedure

The principal investigator searched through the databases identifying potential articles for inclusion. The first screening step reviewed titles and abstracts utilising the eligibility criteria. Once articles for potential inclusion were identified, they were reviewed by two other members of the research team. The principal investigator then read through all articles and presented summaries to the other researchers in the form of a 'data charting' form. Using this form, an iterative discussion occurred between the three members of the research team to develop a final list of articles for inclusion.

3.4 Results

The original search, conducted from November 2015 to January 2016, produced a total of 589 articles for potential inclusion. From these articles, 30 titles were identified as relevant and examined further to identify whether they met inclusion criteria. Following an iterative review process of these 30 articles, 12 met final inclusion criteria, refer to Figure 3.1 for further information on the review process.

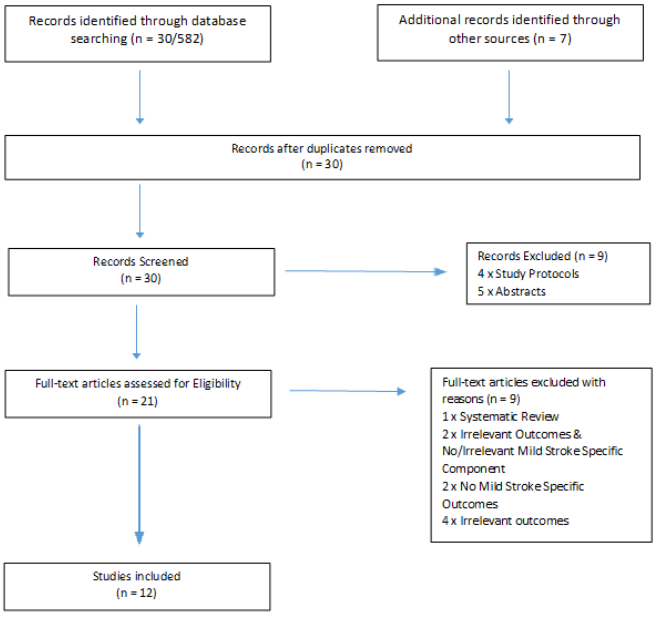

Figure 3.1: Study Selection

3.4.1 Critical Appraisal

There were a number of different methodological approaches utilised to assess the mild stroke services within the current evidence-base. Randomised controlled trials (RCTs) were used for five studies, with the other seven utilising various non-randomised methodologies, see Table 3.1. Scores obtained from the *Downs and Black Checklist* (Downs & Black, 1998) regarding the methodological quality of these articles ranged from 15/28 to 23/28. A search of OTseeke*r* and PEDro for current critical appraisals of the included articles was completed for comparison. PEDro yielded critical appraisals for the Boss and colleagues (2014), Faulkner and colleagues (2015) and Ytterberg, Malm and Britton (2000) studies, and reported scores of 5/10, 6/10 and 2/10 on the PEDro scale. The PEDro scale is an 11-item scale designed for rating the methodological quality of RCTs and has acceptable reliability, based on consensus judgements (Maher, Sherrington, Herbert, Moseley & Elkins, 2003). The findings from the PEDro database, were relatively similar to the critical appraisal scores, with respective ratings of 21/28, 21/28 and 15/28, demonstrating similar ratings in the prior two studies, whilst the latter is substantially lower.

Blinding was the dominant methodological flaw that was apparent within studies. All twelve studies were unable to blind participants and nine were unable to blind outcome assessors impacting internal validity. Lapses in reporting within studies also reduced scores. Eight studies failed to report potential adverse events, eleven failed to report the representativeness of the sample to its source population and six did not give recruitment dates. The seven non-randomized trials lost points for randomization, with an additional RCT also losing points for concealment of randomization. Finally, half the studies lost points due to power and the lack of a power equation.

3.4.2 Study Location

Most research was completed in the Northern Hemisphere, with only one study completed in the Southern Hemisphere (Figure 3.2). In the Northern Hemisphere, the United Kingdom (UK) and Western Europe appear to be significant research locations, along with the north-eastern point of the United States of America (USA) in conjunction with the south-eastern point of Canada. A limited eastern perspective is provided, with two studies located in China and Taiwan.

Number & Authors	Location
1. Adie & James 2010	Devon, United Kingdom (UK)
2. Allen et.al. 2002	Akron, Ohio, United States of America (USA)
3. Arts, Kwa & Dahmen 2008	Amsterdam, The Netherlands
4. Boss et.al. 2014	Amsterdam, The Netherlands
5. Faulkner et.al. 2015	Wellington, New Zealand
6. Kamm et. al. 2014	Bern, Switzerland
7. Prior et.al. 2011	London, Ontario, Canada
8. Rochette et.al. 2013	Montreal, Quebec, Canada
9. Sides et.al. 2012	Winston-Salem, North Carolina, USA
10. Sit et.al. 2007	Hong Kong, China
11. Wang et.al. 2013	Taichung, Taiwan
12. Ytterberg et.al. 2000	Stockholm, Sweden

Figure 3.2: Location of Studies

3.4.3 Types of Interventions & Intervention Outcomes

There were five main types of post-acute hospital discharge services developed and discussed. These included: telehealth programs, exercise programs with education, comprehensive cardiac

rehabilitation (CCR) programs, one-off visits with care-plan development, and community group programs, see Table 3.1.

3.4.3.1 Telehealth Programs

Three studies explored the use of telehealth services for people with mild stroke. Each of these studies had differing intervention lengths and focal points (Adie & James, 2010; Rochette et al., 2013; Sides et al., 2012). Whilst Sides and colleagues (2012) and Adie and James (2010) both targeted secondary prevention, they approached this slightly differently with one targeting medication management (Prior et al., 2011) and the other focusing on lifestyle change (Sides et al., 2012). Rochette and colleagues (2013) moved away from purely secondary prevention and promoted a problem-solving approach for a wide range of new and ongoing issues. All three interventions produced limited significant findings, but positive trends were observed. The studies that focussed on secondary prevention demonstrated increased knowledge in accessing healthcare (Sides et al., 2012) and medication (Adie & James, 2010), as well as trends toward lower depression scores, higher reported health status and reduced disability (Sides et al., 2012). Rochette and colleagues' results (2013) were positive from a qualitative perspective in terms of: appreciation of support, better problem solving abilities and increased insight (see Table 3.1).

3.4.3.2 Exercise with Education Program

The use of exercise programs in combination with education for secondary prevention was reported in two studies, with differing intervention periods and approaches (Boss et al., 2014; Faulkner et al, 2015). Significant findings were reported mainly in relation to physical outcomes. These findings were represented with improvements in the physical component score of the Short Form Health Survey-36 (p=<0.01), including its subdomains (Faulkner et al., 2015), and attainment of composite endpoint of optimal therapy (Boss et al., 2014). Composite endpoint of optimal therapy was defined as the combination of prescribed antithrombotic therapy and achievement of both blood pressure and LDL cholesterol targets (Boss et al., 2014). Neither study demonstrated improvement in emotional well-being or other secondary prevention indicators.

3.4.3.3 Comprehensive cardiac rehabilitation

Two studies utilised comprehensive cardiac rehabilitation altered for people with mild stroke (Kamm et al., 2014; Prior et al., 2011). Both resulted in significant positive findings in regards to secondary prevention health indicators such as: aerobic (p=<0.001) (Prior et al., 2011) and exercise capacity (p=<0.000) (Kamm et al., 2014), blood pressure (p=<0.008) (Kamm et al., 2014), BMI (p=0.005; p=0.003) (Kamm et al., 2014; Prior et al., 2011), low-density lipoprotein (p=0.033, p=0.015) (Kamm et al., 2014; Prior et al., 2011), triglycerides (p=0.001, p=0.003) (Kamm et al.,

2014; Prior et al., 2011), smoking (p=<0.000) (Kamm et al., 2014), total cholesterol (p=<0.001), and waist circumference (p=<0.001) (Prior et al., 2011). Additionally, Kamm and colleagues (2014) found a reduction in the number of people with anxiety and depression post intervention, however, these scores were not significant (HADS-A p=0.085; HADS-D p=0.376).

3.4.3.4 One-Off Day Visits with Care Plan Development

Three studies approached the provision of services by developing one-off day programs that targeted future care needs (Allen et al., 2002; Arts, Kwa, & Dahmen, 2008; Rochette et al., 2013; Ytterberg et al., 2000). There appeared to be a difference in the comprehensiveness of researchers' approaches to this style of intervention. All programs included an assessment session with provision of relevant information and advice (Allen et al., 2002; Arts et al., 2008; Ytterberg et al., 2000), but only Allen and colleagues (2002) included development of a formal treatment plan. The most significant results were demonstrated by Allen and colleagues (2008), where high levels of satisfaction and significant results in the intervention group were observed in regards to global effectiveness (p=<0.001). This was defined as the difference between the two groups in: neuromotor function, severe complications, quality of life, management of risk and stroke knowledge. Significant findings in the remaining studies were mainly in regards to satisfaction (Arts et al., 2008; Ytterberg et al., 2000), although Ytterberg and colleagues (2000) also reported a positive impact on depressive symptoms, hospitalisations and seeking of healthcare assistance.

3.4.3.5 Community Education Programs

Two studies consisted of nurse-led community education programs that focussed on secondary prevention (Sit et al., 2007; Wang, Chen, Liao & Hsiao, 2013). The results obtained from both studies were positive in regards to reducing stroke indicators, which included: stroke knowledge (p=<0.001) (Sit et al., 2007), health maintenance behaviours (p=<0.001), dietary factors and habits (p=0.04) (Sit et al., 2007; Wang et al., 2013), and risk factors of stroke (p=<0.001) (Wang et al., 2013).

Table 3.1: Summary of Studies

Study	Intervention Type (&/or comparator)	Study Population Characteristics	Aims of the Study	Outcome Measures	Important Results
Adie & James 2010 **Design:** RCT **Size:** N = 56 **Setting:** Community **Location:** Devon & Exeter, UK **Downs & Black:** 22/28	**I:** Routine management + Telephone follow-up. Targeted lifestyle change through goal-planning. **C:** Routine management (no secondary care visits). **Duration:** 4 months + Follow-up at 6 months.	**Inclusion Criteria:** 1.18+ years 2 Minor stroke or TIA 3. SBP = ≥140mmHg 4. Living at home **Exclusion Criteria:** 1. Dementia 2. Significant disability or co-morbidity which would impair ability to consent or cause undue distress.	To investigate the effect of telephone follow-up on the uptake of secondary prevention in hypertensive patients.	**Primary Outcome Measure:** Difference between I and C groups in 12h ambulatory SBP change from baseline to 6 months. **Secondary Outcomes:** Differences in: - Antihypertensive and cholesterol-lowering medication. - Random total cholesterol. - Self-reported exercise. - No. of healthcare contacts. - Smoking status. - Medication knowledge.	Telephone support is insufficient to increase patient participation in customary dose-titration regimens. **Primary Outcome**: I: 0 mm Hg, C: 3 mm Hg. Change in SBP not significant between groups. **Secondary Outcomes:** No significant differences between groups in: weight, total cholesterol, exercise duration, HRQOL, no. of healthcare contacts or BP medications. Medication knowledge was significantly higher in TFU group at follow-up. At 6 months all (2) smokers in I group had given up smoking, compared to 3/8 for C group.

Allen et. al. 2002 **Design:** RCT **Size:** N = 96 **Setting:** Community **Location:** Akron, Ohio, USA **Downs & Black:** 21/28	**I:** APN-CM (Advanced Primary Nurse Care Manager) home visit 1 month post-discharge. Standardized biopsychosocial assessment completed and individualised treatment plan developed. **C:** Standard care provided by PCP (Primary Care Practitioner). **Duration:** 3 months	**Inclusion Criteria:** 1. Ischemic stroke or TIA. 2. Admitted from and discharged to home or to short-term rehabilitation. 2. mRS score ≤3. 3. No other illnesses that would dominate their post-discharge care.	To measure the effectiveness of a comprehensive interdisciplinary post-discharge stroke care management model in improving a profile of indicators of health recovery, maintenance, and secondary prevention in stroke/TIA survivors as compared to stroke/TIA survivors who received usual post-discharge care.	**Neuromotor Function:** Sum of NIHSS and Barthel Index scores. **Severe Complications:** Indirect measure of severe post-discharge complications indicated by re-institutionalisations or death. **Quality of Life:** Stroke Adapted 30-item Sickness Impact Profile version (SA-SIP30). **Management of risk for common negative post-stroke outcomes and recurrent stroke:** 1. BP 2. Depression 3. Falls 4. Medication appropriateness. **Stroke Knowledge:** Multiple choice test.	**Global Effectiveness (average of the differences between the 2 groups across the 5 domains):** I group superior to C group (P<0.0001). **Effect Sizes for Individual Domains:** Largest effect size was Stroke Knowledge (0.98). Smallest effect size was Neuromotor Function (0.10). **Secondary Analyses:** Excluding Barthel Index and falls, every variable was better in I group compared to C group. Surveys indicated acceptance and a high satisfaction.

Arts et. al. 2008 **Design:** Pilot Intervention Study **Size:** N = 42 **Setting:** Outpatient Clinic **Location:** Amsterdam, The Netherlands **Downs & Black:** 15/28	**I:** Visit to rehabilitation department of hospital at 4-6 wks after discharge. AMPS performed by OT and neuropsychological screening by neuropsychologist. Advice provided regarding further therapy after assessment. **Duration:** 6 weeks + Follow Up at 6 months.	**Inclusion Criteria:** 1. TIA or minor stroke. **Exclusion Criteria:** 1. Patients who received treatment directly after discharge. 2. Apparent residual neurological deficits (mRS 2≤).	To evaluate the satisfaction of stroke patients who participated in the 'indivdualised stroke care programme' and to identify the factors that are possibly related to patient satisfaction.	**Primary Outcome Measure:** Home Subscale of the Satisfaction with Stroke-Care questionnaire (SASC-19). **Secondary Outcome Measures:** 1. Ability to perform Activities of Daily Living (Barthel Index) 2. Overall degree of independence (mRs). 3. Anxiety and depression (Hospital Anxiety and Depression Scale [HADS]). 4. QoL (Short Form 36 [SF-36]).	**Primary Outcome:** 71% satisfied with outpatient care. Of the 16 patients who accepted therapy, 67% were satisfied with outpatient care. **Secondary Outcome:** Dissatisfied patients had a significantly higher score than satisfied patients on the mRS. Dissatisfied patients were more depressed than satisfied patients. QoL was lower for dissatisfied patients on SF-36, only subscales of Bodily Pain and Social Functioning were significant. **Qualitative data:** Satisfied patients felt that the program raised their confidence and hope, but also found the assessments very intensive.
Boss et. al. 2014 **Design:** RCT (Pilot study, Single-blinded) **Size:** N = 20 **Setting:** Outpatient Clinic	**I:** Post-stroke care program with exercise. Patients visited outpatient clinic at 4 wks, 3-, 6- & 9- mths after stroke. Pharmacological therapy, motivational interviewing based counselling strategy	**Inclusion Criteria:** 1. 18 yrs+ 2. Minor ischemic stroke or TIA (NIHSS ≤3) 3. Onset of symptoms <1 week 4. Independently able to walk. 5. Discharged without	To study the safety and feasibility of a post-stroke care program including an exercise program in the acute phase after minor ischemic stroke or TIA. **Additionally:** to investigate the effect of the program on	**Primary Outcome Measures:** - Safety: Adverse and all new vascular events. - Feasibility: no. of patients who completed the intervention and follow-up at 1 yr.	**Primary Outcome Measures:** Safe and Feasible: no cardiac or pulmonary contraindications and all patients completed follow-up at 1 yr and 18 completed intervention. **Secondary Outcome Measures:** 45% reached the composite endpoint of

Location: Amsterdam, The Netherlands **Downs & Black:** 22/28	and 8 wk aerobic and strength training exercise program. **C:** Post-stroke care program: Same as the I group; however, without the exercise program. **Duration:** 1 year + Follow-up at 6 & 12 months.	need for further rehabilitation **Exclusion Criteria:** 1. Dementia/MMSE score <24 2. Aphasia/language barrier 3. Cardiopulmonary contra-indication for physical exercise and exercise testing 4. Chronic disease with an expected survival <2 yrs	cardiorespiratory fitness and secondary prevention targets.	**Secondary Outcome Measures:** - Cardiorespiratory Fitness: Maximal exercise capacity: VO2max or ml/Kg/minute. - Symptom-limited ramp exercise test. - Measures of secondary prevention: no. of patients who achieved the composite endpoint of optimal medical therapy, medication adherence, smoking, alcohol consumption, BMI and waist circumference.	optimal therapy, 7/10 I group vs. 2/10 C group (p=0.04). No significant differences were found between groups in BP or LDL-c levels or the rate of smoking cessation, alcohol consumption, medication adherence, BMI and waist circumference at 12 months.

Faulkner et. al. 2015 **Design:** RCT (parallel group, single-centre) **Size:** N = 55 **Location:** Wellington, New Zealand **Downs & Black:** 20/28	**I:** 2 x exercise sessions & 1 education session per wk for 8 wks. Exercise sessions: 30mins of aerobic exercise and 60 mins of resistance training, core-stability and postural exercises. Education sessions: Group discussion to increase understanding and management of condition. **C:** Standard secondary prevention and educational information from the hospital. **Duration:** 8 weeks + Follow-up at 8 week and 12 months	**Inclusion Criteria:** 1. TIA or a mild/non-disabling stroke. 2. Residence within the local District Health Board. **Exclusion Criteria:** 1. Unstable Cardiac Conditions. 2. Uncontrolled Diabetes Mellitus. 3. Severe Claudication. 4. Oxygen dependence. 5. Significant Dementia. 6. Inability to communicate in English. 7. Unable to take part in exercise.	To assess the effect of an exercise and education program implemented soon after TIA or mild/non-disabling stroke diagnosis, on psychosocial health outcomes in both the short- and long-term.	**Primary Outcome:** - Short-Form 36 SF-36 **Secondary Outcome:** - Hospital Anxiety and Depression Sales (HADS) - The Profile of Mood States. - International Physical Activity Questionnaire - Stanford Medical Centre Stroke Awareness Questionnaire	**Primary Outcome:** Significant difference in Physical Component Score of SF-36 in I group, but not in C group ($P<0.01$). Similar findings for sub-domains: vitality, global health, role physical, and physical functioning (all $P<0.05$). **Secondary Outcomes:** Hospital Anxiety & Depression Scale: No difference. **Profile of Mood States:** Significant difference observed in Fatigue for I group between 8wk & 12 mth follow-up ($P<0.01$). **Stroke Awareness Questionnaire:** I group demonstrated greater overall awareness of the signs and symptoms of stroke compared to C group ($P<0.05$). **International Physical Activity Questionnaire:** decrease in physical exertion, and significant increase in sitting behaviour between 8wk and 12 mth follow-up.

Kamm et. al. 2014 **Design:** Prospective, single-center interventional cohort study. **Size:** N = 105 **Location:** Bern, Switzerland **Downs & Black:** 18/28	**I:** 3-mth hospital-based outpatient CCR (Comprehensive Cardiac Rehabilitation) program: 36 hrs Physical therapy & 12 hrs of lectures and counselling. Physiotherapy: 1hr of aerobic exercise + 1hr of defined exercise to address specific patient issues + 45 mins of aerobic ergometer training. Lecture Topics: etiology, diagnosis, treatment and prevention of stroke; vascular risk factors; nutrition counselling; active and passive smoking cessation and psychological coping strategies. **Duration:** 3 months	**Inclusion Criteria:** 1. TIA or stroke 2. 18-80 yrs 3. Physical and cognitive functions had recovered well enough to attend the outpatient exercise and teaching program. 4. At least 1 risk factor, e.g. hypertension. **Exclusion Criteria:** 1. Intracranial haemorrhage. 2. Disabling stroke. 3. Other conditions that compromise participation and proper performance of the program.	To describe the combined secondary prevention and neurorehabilitation program and its impact on vascular risk factors, neurologic functions and Health Related Quality of Life (HRQOL).	**Functional Tests to evaluate Physical Skills:** - 9-Hole Peg Test (9-HPT) - 6 Min Walking Test (6MWT) - One Leg Stand (OLS) - Ability to walk back/forward 3m on a bench **HRQOL:** - Short-Form Health Survey-12 (SF-12) - Hospital Anxiety and Depression Scale (HADS) **Feasibility:** - The integration of neurorehabilitation into an existing CCR program without significant adaptation and interference of the structures of the rehabilitation centre as well as the practicability and acceptance of the program by patients.	**Feasibility:** No serious adverse events and program was feasible. Good practicability and adherence (dropout rate = 9.5%). Average patient satisfaction on VAS = 8.8 (range = 7-10) **Secondary Prevention:** BP, BMI, low-density lipoprotein, triglycerides and smoking were significantly reduced. Maximal exercise capacity corresponded to a normal exercise capacity for age at program end. Only 7% had elevated BP at program end (34% at baseline). **Physical Skills:** 9-HPT values improved significantly. Submaximal exercise tolerance (6MWT) increased by 10% in all patients. OLS test values improved significantly. **HRQOL:** The physical score of the SF-12 increased significantly. 71% of 17 patients with borderline pathological HADS - A values improved, 47% showed no more signs of anxiety. 69% of 13 patients with borderline or pathological HADS - D

- Serious adverse events.	values improved, 54% showed no more signs of depression.

Prior et. al. 2011 **Design:** Feasibility Study **Size:** N = 100 **Location:** London, Ontario, Canada **Downs & Black:** 18/28	**I: Comprehensive Cardiac Rehabilitation (CCR):** Nurse case management throughout CCR, including orientation and 3 month visit/telephone call. Exercise Program offered an on-site 2xweekly, 50-session option, with supplementary home-based training OR a home-based option, with exercise at least 4xweekly + monthly contact. A dietitian delivered nutrition counselling. Clinical psychologist referrals occurred as needed. **C:** Usual stroke prevention clinic care, comprised of best practice guidelines and standard secondary prevention advice. **Duration:** 6 months	**Inclusion Criteria:** 1. 20 years+ 2. TIA/Mild Non Disabling Stroke (MNDS) within 12 months. 3. ≥1 risk factor, e.g. hypertension. 4. English speaking. **Exclusion Criteria:** 1. Intracranial haemorrhage. 2. Anticipated or recent (<30 days) carotid endarterectomy or percutaneous coronary intervention. 3. Evidence of disabling stroke or dementia. 4. Previous participation in CCR. 5. Unable to perform CCR exercise training. 6. Participation in another clinical study that would interfere with intervention or outcomes.	Hypothesized that an existing 6-month CCR program, in collaboration with a stroke prevention clinic (SPC), could provide feasible, effective secondary prevention following TIA/MNDS, without duplication of infrastructure & expertise. Article reports the risk factors and intermediate outcomes.	**Key risk-related outcomes:** - Aerobic capacity - METS - Total Cholesterol (TC) - High-density lipoprotein (HDL) - Triglycerides - Fasting blood glucose - systolic (SBP) and diastolic blood pressure (DBP) - Waist circumference - BMI - Body weight - Smoking status - Medications - Mortality risk - Events	**Aerobic capacity:** Significant increase of 2.04 METS (31.4%) in mean aerobic capacity. Proportion of subjects meeting a functional target (7≤ METS) increased significantly from 35.1% to 64.6%. **TC/HDL/Triglicerides:** Decreased significantly. **Fasting Blood Glucose:** No significant change. **SBP & DBP:** No significant change. **Waist Circumference/BMI/Body Weight:** Small significant decreases. **Smoking Status:** 7/14 quit by exit (P=0.008). **Medications:** No significant changes. **Mortality Risk:** mean Duke Treadmill Score (TDS) increased significantly, from 4.49 (SD 6.08) to 7.88 (SD 6.42). **Events:** 1/80 had 2 x TIAs without hospitalisation, 2/80 had 1 x TIA without hospitalisation, 1/80 had carotid stent placement, 1/80 had unstable angina with hospitalization and coronary

angiography. No recurrent strokes.

Rochette et. al. 2013 **Design:** RCT **Size:** N = 186 **Location:** Montreal, Quebec, Canada **Downs & Black:** 23/28	**I (We Call): A** multimodal (telephone, internet and paper) support intervention. Telephone interactions focused on new/ongoing issues, and occurred weekly for 2xmonths, biweekly in 3rd month, & monthly for last 3xmonths. Issues addressed included: family functioning, depression, neurocognitive functioning, functional independence, physical health and individualised risk factors **C (You Call):** Provision of name and phone number of a trained healthcare professional (THCP) who answered queries initiated by participant. **Duration:** 6 months + Follow-up at 1 year	**Inclusion Criteria:** 1. Adults with a first mild stroke (>8.5/11.5 on the Canadian Neurological Scale or 0-2 on mRs). 2. Discharged home <3 weeks of stroke event. 3. Telephone access 2. Ability to understand basic instructions and express basic needs. 3. Ability to communicate in English or French. **Exclusion Criteria:** 1. Moderate-severe cognitive deficits. 2. Experience of another stroke before baseline measures were completed.	To determine whether a low-cost, multi-modal support intervention (WE CALL) offered for 6 months would be effective compared with the availability of a resource person (YOU CALL) in reducing unplanned use of healthcare systems for adverse events and in improving quality of life after intervention and at 1 year follow-up.	**Primary Outcome:** Unplanned use of health services for an adverse event (frequency calendar). Quality of life (Quality of Life Index & Euroquol-5D). **Secondary Outcomes:** - Planned use of health services (frequency calendar). - Depressive symptoms (Beck Depression Inventory II). - Participation (Assessment of Life Habits [LIFE-H 3.1]).	**Primary & Secondary Outcomes:** No significant differences between groups on primary outcomes. **YOU and WE CALL Intervention Results:** 6/94 participants used the YOU CALL intervention. WE CALL participants were reached 78.4% of the time, minimum of 3 attempts for each time point. **Qualitative Findings:** Participants in WE CALL reported: (1) Appreciation of Support, (2) Better problem solving, & (3) Increased insight.

Sides et. al. 2012 **Design:** Two-arm pilot study **Size:** N = 30 **Location:** Winston-Salem, North Carolina, USA **Downs & Black:** 20/28	**I:** Telephone contact from medication coach within 2 weeks of discharge. Contact covered: general stroke information, importance of stroke prevention, modifiable risk factors and importance of adhering to medications. Coach reviewed medications, participant's understanding and checked compliance. Coach triaged participant questions to appropriate health professionals, compiled responses and called participant with information. Information summarised and sent to participant's PCP. **C:** Not contacted by medication coach. **Duration:** 2 weeks + Follow-up at 3 months	**Inclusion Criteria:** 1. Ischemic or hemorrhagic stroke/TIA 2. At least 2 medications changed between admission and discharge. 3. Discharged to home	1. Assess the feasibility of the intervention in terms of the appropriateness of script, ability to reach participants, and provide the requested information. 2. Assess the preliminary impact of the intervention on medication knowledge, medication persistence, and appointment-keeping.	**Primary Outcomes:** 1. Feasibility of the intervention (ability to reach participants, number of attempts, and time spent on the telephone). 2. Participants' evaluation of the medication coaching and its implementation. **Secondary Outcomes:** 1. Impact of intervention on medication persistence, knowledge, and appointment keeping. 2. Clinical and functional outcomes. 3. Resource utilization (re-hospitalisations and Emergency Department visits).	**Primary Outcome - Follow-up calls and Logistics:** 14/19 required more than 1 phone call. Median number of calls required was 2(1-9). 4/29 could not be contacted at 3 month interview. 20/37 interviews completed after 3 months. Number of attempts for follow-up ranged between 1 and 30 calls**.** **3 month follow-up outcomes**: Little difference in groups in reported levels of knowledge or understanding about medications/stroke. More I group participants knew what to do if problems or symptoms continued/worsened (93.8% vs. 77.8%). Larger proportion of I group participants had seen their PCP between discharge & 3 months (93.8% vs. 60%). Trends towards lower depression severity score, higher reported health status and lesser disability in I group. Persistence with discharge medication use similar in both groups (87.5% IG & 88.9% CG).

Assessment of medication knowledge during coaching calls: 7/19 I group participants were able to identify why they were taking all of their medications and 9/19 could state the reason for taking 50%≤. Most could explain how to refill medications. None could identify 1 side effect for all prescribed medications. 5/19 unable to list any side effects. All participants taking warfarin were able to identify at least 1 side effect and knew regular blood tests were required.

Sit et. al. 2007 **Design:** Quasi-experimental study **Size:** N = 147 **Location:** Hong Kong, China **Downs & Black:** 21/28	**I:** Group Program run by Registered Nurses - 8 x 2 hr sessions, 1 session per wk. Each session used teaching, games, experience sharing, and experimental learning methods. Focus on individual goal setting and action plans. **C**: Conventional treatment & health promotion pamphlets on stroke/stroke prevention. **Duration:** 8 weeks + Follow-up at 1 week & 3 months.	**Inclusion Criteria:** 1. 18+ yrs 2. Minor stroke. 3. Medically stable. 4. Independent in ADLs. 5. Cognitively intact. 6. Able to communicate in Cantonese. 7. Living in the community and not receiving/pending surgical treatment. **Exclusion Criteria:** 1. Congenital cerebrovascular abnormality. 2. Haemorrhagic stroke/ stroke-like syndromes from other causes.	Focused on the knowledge and behavioural components of a secondary stroke prevention project examining the effectiveness of a community-based stroke prevention programme for people with minor stroke.	**Stroke Knowledge:** Knowledge of stroke scale (modified). **Self-health-monitoring practice:** Questionnaire used to examine whether the subject had performed regular self-health checking on BP, blood sugar, cholesterol, triglyceride level, urine testing. **Health behaviours:** - Medication compliance scale - Self-reported cigarette and alcohol consumption. - Exercise scale (modified). - Self reported dietary intake in previous 2 weeks.	Statistically significant improvements were found in I group in: 1. Knowledge about stroke warning signs and emergency treatment seeking response during suspected stroke (P<0.001). 2. Health maintenance behaviours including medication compliance (P=0.004) and daily self BP monitoring (P<0.001). 3. Dietary habits. No significant change was found for other lifestyle factors, including: smoking, alcohol drinking, and consumption of deep-fried and light-fried food.
Wang et. al. 2013 **Design:** Non-	**I:** Community-based stroke nursing education and	**Inclusion Criteria:** 1. Mild Stroke 2. MMSE: 20≤	To evaluate whether patients with mild stroke who received a community-based stroke	**Questionnaire Covering the following areas:**	**Knowledge & Behaviour:** I group experienced significant improvement in

randomized Trial **Size:** 170 participants **Location:** Taichung, Taiwan **Downs & Black:** 16/28	rehabilitation program for 8 weeks, with 3 x 2 hr sessions per week. Stroke educational sessions and communication seminars alternated with participant support groups. Seminar content included: warning signs, clinical manifestations, stroke risk factors, diet, social activities and rehabilitation. Group communication component included: discussion and sharing of rehabilitation experiences. **C**: Received a general stroke education program and participated in hospital-based post-stroke education and rehabilitation programs. **Duration:** 8 weeks + Follow-up at 3 & 6 months after baseline.	3. No psychiatric illness. 4. Barthel Index: 65≤ **Exclusion Criteria:** 1. Multiple strokes. 2. Severe language and hearing impairments that could interfere with evaluation interviews.	nursing education and rehabilitation program had better knowledge, behaviour and self-efficacy compared with those who were exposed to traditional education programs in a hospital setting.	- Demographic characteristics - Lifestyle (smoking/drinking) - Chronic diseases. - Knowledge & behaviour related to stroke and stroke risk - Social participation - Self-efficacy - Self-care	knowledge scores including warning signs, medical treatment (P<0.001), risk factors of stroke (P<0.001) and dietary factors following intervention. Significant difference in warning signs and medical treatment remained at 6-month follow-up. Similar trend in knowledge scores of risk factors in I group in all 3 evaluations. I group had significant difference in mean knowledge score of risk factors, increasing at 6 month follow-up in comparison with baseline and C group (P=0.04). Significant difference in behaviour scores during baseline, post-intervention and 6 month follow-up in I group (P<0.001). **Self-Efficacy:** Gradually increasing at 6 month follow-up in I group (P<0.001). Self-efficacy was significantly correlated with knowledge of risk factors at 3 (P=0.02) and 6 month follow-ups (P<0.01) in I group.

Ytterberg et. al. 2000 **Design:** Non-Randomized Trial **Size:** N = 111 **Location:** Stockholm, Sweden **Downs & Black:** 19/28	**I:** Follow-up visit 1mth after discharge. Visit included appointments with counsellor, PT, OT and nurse. Each conducted own assessments, and results/need for action were discussed in consultation with GP. Participants were invited to take part in a weekly information session for hospitalised/discharged patients and their relatives. **C:** Treated in accordance with the usual routine without follow-up visits. **Duration:** One off visit + Follow-up at 3 months.	**Inclusion Criteria:** 1. Stroke patients discharged directly home with mild stroke. 2. Not given any unified, inpatient rehabilitation, home rehabilitation or day care.	To answer the question: whether by systematic evaluation of patients 1 month after discharge, one could detect negative developments in time and thus take action which could improve the end result.	**Questionnaire containing the following:** - The Nottingham Health Profile questionnaire (NHP) – QoL - Non-Verbal QoL Visual Analogue Scale. - Questions regarding healthcare consumption following discharge. - Questions regarding ADL capability. - Questions regarding the patient's satisfaction with care.	**Outcome of All-Day Follow-up Visit:** Follow-up visits led to concrete courses of action in 10 (20%) of patients. Results from motor function, cognition and ADL assessments led to action in 5 cases. Test results for Depression led to measures being taken in 5 cases. **Follow-up after 3 months:** Participants in I group were more satisfied with their care in only one respect - the therapy they received. Participants in I group sought medical help to a lesser extent than C group. No overall difference in quality of life between groups. I group had 19 participants that had results indicative of depression, vs. 12 in C group at discharge. I group had 13 participants have results indicative of depression at 3 months vs. 11 in C group.

3.5 Discussion

This review aimed to identify the current evidence-base surrounding services available to assist people with mild stroke with person-centred secondary prevention and adaptation to post-stroke changes. It should be noted though that studies may have been missed that explored interventions that catered for people with mild stroke but included people with all stroke severities. Findings demonstrate a number of different approaches to service provision, however it appears that current approaches do not comprehensively meet the diverse needs of people with mild stroke. Gaps in the evidence-base will be discussed in order to inform future service development.

A range of treatment approaches were utilised in studies, however many focused on the secondary prevention of stroke. Eight studies attempted to reduce stroke indicators and increase healthy lifestyle behaviours, with a mix of results observed (Adie & James, 2010; Boss et al., 2014; Faulkner et al., 2015; Kamm et al., 2014; Prior et al., 2011; Sides et al., 2012; Sit et al., 2007; Wang et al., 2013). The literature demonstrates that people with mild stroke experience a number of changes in their lives following acute hospital care that extend beyond secondary prevention. Some of the most impacted areas include: executive functioning (Adamit et al., 2015; Carlsson et al., 2009; Jacquin et al., 2014; Srikanth et al., 2003; Wolf et al., 2011; Wolf et al., 2013), fatigue (Carlsson et al., 2003; Flinn & Stube, 2010; Green & King, 2007; Hildebrand et al., 2012; Kim et al., 2015; Kristensen et al., 2010; O'Brien & Wolf, 2010; Tellier & Rochette, 2009), employment (Carlsson et al., 2003, 2009; Edwards et al., 2006; Green & King, 2007, 2011; Johansson et al., 2007; Kristensen et al., 2014), performance in daily life activities (Carlsson et al., 2003, 2004, 2009; Edwards et al., 2006; Green & King, 2007, 2011; Hildebrand et al., 2012; Rochette et al., 2007; Seymour & Wolf, 2014; Tellier & Rochette, 2009) and emotional wellbeing (Carlsson et al., 2004, 2009; Edwards et al., 2006; Green & King, 2007; Gustafsson & Tuprin, 2012; Hommel et al., 2009; Johansson et al., 2007; Kristensen et al., 2014; Taule & Råheim, 2014; Wolf et al., 2009; Verbraak et al., 2012). The experience of disability is a complex interaction of the health condition, contextual factors, and how a person perceives themselves and their role in society (Berzina, Smilskalne, Vetra, & Sunnerhagen, 2016). The majority of secondary prevention studies in this review did not directly target individual emotional-wellbeing (Adie & James, 2010; Boss et al., 2014; Faulkner et al., 2015; Kamm et al., 2014; Prior et al., 2011; Sides et al., 2012; Sit et al., 2007), therefore a key element of the disability experience was not addressed. It must also be noted that these interventions focussed at a person and impairment level, with limited attention placed on performance in daily life, particularly complex activities, consequently neglecting contextual factors. Overall, whilst this style of intervention can contribute to the prevention of further strokes, its ability to assist with the adaptation to ongoing issues in the person's life is limited.

Two further studies were identified that focussed at an impairment level; however, these took a more individual-, assessment-based approach to services and were executed using one-off day visits (Arts et al., 2008; Ytterberg et al., 2000). The efficacy of this particular approach to mild stroke services cannot be established from the two studies identified. The primary outcome of Arts and colleagues (2008) study was satisfaction and whilst this was positive, it does not inform of the intervention's ability to assist people with mild stroke to adapt to ongoing changes in their life or to prevent a further stroke. Ytterberg and colleagues (2000) found no statistical differences between their two study groups, with the intervention group only demonstrating a higher level of satisfaction with the care they received.

There were two studies that utilised interventions with a more person-centred approach. The first of these was Allen and colleagues' (2002) APN-CM program, which identified significant positive results. The use of a biopsychosocial assessment in this study resulted in an enhanced ability to incorporate contextual factors, however its capacity to target more complex activities remains unclear as these were not discussed. The second study, Rochette and colleagues' telehealth approach (2013) was unable to yield significant quantitative results, however, qualitative reports demonstrated an appreciation for the program and improved problem-solving skills and insight. Quantitative outcome measures in this study may have lacked sensitivity to changes in executive functioning and complex activities, possibly explaining the absence of significant results. As qualitative findings were positive, further research is recommended in combination with quantitative outcome measures sensitive to difficulties associated with mild stroke.

The relatively short intervention and follow-up period evident in a number of the studies was a notable finding in this review. It has been suggested that the critical transition period of community reintegration for people with acquired brain injury (ABI), including stroke, is that of the first three to 6 months post hospital discharge (Hall et al., 2012; Turner et al., 2007). Within this phase, the positive perception of recovery associated with functional improvements in the first 2 months after the stroke event is altered when people with mild stroke begin to experience difficulty in re-establishing daily routines (Green & King, 2011). It may therefore be supposed that the entire transition phase of 6 months should be incorporated into services for this population. Only three studies delivered interventions that targeted the entire transition period (Boss et al., 2014; Prior et al., 2011; Rochette et al., 2013), with the remaining interventions ranging from 2 weeks to 4 months (Adie & James, 2010; Allen et al., 2002; Arts et al., 2008; Faulkner et al., 2015; Kamm et al., 2014; Sides et al., 2012; Sit et al., 2007; Wang et al., 2013; Ytterberg et al., 2000). The ability of these interventions to provide assistance for changes that occur beyond the initial months after stroke is therefore limited. Furthermore, only seven of the studies had follow-up periods of at least 6 months

(Adie & James, 2010; Arts et al., 2008; Boss et al., 2014; Faulkner et al., 2015; Prior et al., 2011; Rochette et al., 2014; Wang et al., 2013), with five studies having a follow-up period of 3 months (Allen et al., 2002; Kamm et al., 2014; Sides et al., 2012; Sit et al., 2007; Ytterberg et al., 2000). These five studies are consequently limited by their inability to display the effects of their interventions during the latter half of the transition period. Further research that incorporates interventions that cater for the entire transition period, with adequate follow-up is therefore indicated.

Pathways for future development in service provision for people with mild stroke, post-acute-hospital care were identified through this review. Services should incorporate the whole transition period and focus on maximising participation in daily life and secondary prevention, as well as managing post-stroke emotional well-being. In deciding upon how to conduct studies, researchers may consider adding a qualitative component to the often favoured RCT design (Dobrow et al., 2006), as decision-making may be guided further through the identification of people's experiences of services (Taylor & Francis, 2013). When conducting RCTs, attention should be paid to blinding, however as this can be difficult in allied health intervention studies, quality assessment tools that take this into consideration may be needed. Attention to adequate reporting of future interventions is required, as this was deficient in the critical appraisal of studies and aligns with previous research on health reporting (Hoffmann et al., 2014). Endorsed writing guidelines, such as the Template for Intervention Description and Replication checklist and guide (TIDieR) may be able to assist with this and could potentially increase the impact of health research (Hoffmann et al., 2014).

Study location and the types of participants that studies include are the final two areas that have potential for growth. Within this review, nine articles incorporated people with both mild stroke and TIAs (Adie & James, 2010; Allen et al., 2002; Arts et al., 2008; Boss et al., 2014; Faulkner et al., 2015; Kamm et al., 2014; Prior et al., 2011; Sides et al., 2012; Sit et al., 2007), with only three focussing on people with mild stroke alone (Rochette et al., 2013; Wang et al., 2013; Ytterberg et al., 2000). Including people with both TIA and mild stroke has the potential to blur results of intervention efficacy as those with TIA may react differently to people with mild stroke. Further research that solely incorporates people with mild stroke is required to solidify results. Finally, it is clear from Figure 3.2 that with the slight exception of one study conducted in New Zealand and two in Asia, most of the research has been completed in two major regions. Consequently, there is an absence of context-specific research in a number of places, which can impact on service implementation due to feasibility being subject to location circumstances (Hoffmann et al., 2014). For this reason, further research is indicated in the Southern Hemisphere, Asia, Eastern Europe and the western parts of the USA.

3.6 Conclusion

Research into the mild stroke services evidence-base is continuing to gain momentum. By drawing upon current knowledge in this field, researchers can continue to transform service provision for people with mild stroke in order to meet the ongoing changes in their life and prevent further stroke. It is clear from this review that further mild stroke specific research is justified in a number of regions in the world. Services that target complex, activity-level changes, taking into consideration contextual and social factors is proposed for future research. Attention to reporting of results and the incorporation of qualitative and mixed-methods data may further enhance this field. With the adoption of these findings, it is hoped that the mild stroke evidence-base can further develop, leading to effective implementation of services for people with mild stroke, consequently improving the lives of this population.

3.7 Scoping Review Update – May 2019

An updated search was completed in May 2019, following the same procedure outlined in the scoping review. From this search, three new articles were identified. One article related to an intervention reported in the scoping review and two were new studies. Below, a brief description of each of these studies has been given, however the main purpose of providing this information is to alert the reader to new findings in the field.

Heron and colleagues (2017), reported positive findings from their feasibility study conducted in Ireland which involved a novel adapted home-based cardiac rehabilitation program, administered at 4-weeks post first TIA or minor stroke. The study included three groups, a standard care group, a group that received a home-based cardiac rehabilitation program, and a group that received a home-based cardiac rehabilitation program and pedometer or Fitbit (Heron et al., 2017). The cardiac rehabilitation program included a manual and introductory session to explain how to use the manual, provision of medical and social information about TIAs/'minor' strokes and goal-setting education (Heron et al., 2017). Sessions also focussed on topics relevant to cardiovascular risk, community resources, diet and secondary prevention medication (Heron et al., 2017). Standard care was administered as per UK guidelines (Heron et al., 2017). Telephone follow-up was provided by a general practitioner at week one and four of the study for all groups (Heron et al., 2017). Data was collected at baseline and 6-week follow-up (Heron et al., 2017). In total 15 people participated in the study (five in each study group), six of whom had had a minor stroke (Heron et al., 2017). The study found that the group who received the manual and pedometer increased their daily step average by 1407, as well as overall activity levels (Heron et al., 2017). Participants in this group also reported good compliance with wearing the pedometer as recorded in the step-count diary (Herron et al., 2017). Participants who received the manual but not the pedometer also showed an increase in physical activity and reduction in sitting (Heron et al., 2017). The 2-minute walk

distance increased in all groups, with the greatest increase in the group who received the program and had the pedometer (Heron et al., 2017). Hospital Anxiety and Depression Scale scores, particularly for anxiety, improved in both groups who received the cardiac rehabilitation program (Heron et al., 2017). Additionally, qualitative findings demonstrated positive views on the manual, particularly its ability to provide reassurance and support (Heron et al., 2017). The structure and timing of telephone follow-up calls were well received and participants valued having the opportunity to share concerns with and ask questions of a health professional.

In a single-blind, exploratory, randomised controlled trial conducted in America by Wolf, Spiers, Doherty and Leary (2017), the Chronic Disease Self-Management Program (CDSMP) was examined against 'standard care'. The study involved 71 participants with mild stroke, classified with a NIHSS of <6 (Wolf et al., 2017). The CDSMP consisted of two-hour intervention sessions that were conducted once a week for 6 weeks (Wolf et al., 2017). The CDSMP was an education program delivered by an occupational therapist and based on self-management principles, with three main goals: medical management, role management and emotional management (Wolf et al., 2017). Overall, whilst results indicated that there were measurable effects that favoured the treatment group in terms of ability to obtain help from the community, family and friends, and quality of life related to the individuals' environment, these were not clinically significant over a 6-month period (Wolf et al., 2017).

Finally, Prior and colleagues (2017) reported the psychological outcomes of an earlier prospective cohort trial included in the scoping review, that studied the effectiveness of comprehensive cardiac rehabilitation when delivered to people with TIA or mild stroke (please see Chapter 3 for study details). In regards to psychological outcomes in their study they concluded that whilst emotional symptoms, health status and neurocognitive functioning improved significantly, these were not independently associated with comprehensive cardiac rehabilitation (Prior et al., 2017).

3.8 Chapter Summary

This scoping review highlights that there is a need for further investigation into mild stroke specific services, especially within Australia. Further still, it emphasises the need for services that extend beyond secondary prevention and that treat person-level difficulties experienced by people with mild stroke. Finally, it suggests that future studies should utilise qualitative means and extend for at least 6 months in order to cover the entire 'critical' transitional period. Consequently, the research conducted in the subsequent chapters of this thesis will utilise qualitative methods to explore the transitional experiences of people with mild stroke who either receive 'standard care' or a novel stroke-specific self-management telehealth intervention within an Australian context.

Chapter 4: Methodology

This chapter describes the methodological approaches used in the remainder of the thesis. It describes the: purpose, aims and research questions of the thesis, ontological and epistemological positioning of the researcher, research approach used, participant inclusion and exclusion criteria, interventions used during the research project, approach to data analyses and any procedures undertaken. Furthermore, it elaborates on how methodological rigour was maintained during the research and how the PhD candidate demonstrated reflexivity, which must be taken into consideration when interpreting the results chapters of the thesis.

4.1 Purpose, Aim & Key Research Questions

This research project represents a qualitative investigation nested within a randomised controlled trial (RCT). The RCT aimed to determine the efficacy of a new allied health-led, stroke specific self-management model of care for individuals with mild stroke discharged from acute care. The purpose of the current research project was to determine the essence of the transition experience to home after acute hospital discharge for people with mild stroke and their key support person (KSP). Furthermore, it aimed to understand this experience in the context of two different models of care, MiStrEnGTH (MIld STRoke Enhancing and Guiding Transition Home) an allied health-led, stroke specific self-management model of care that uses telehealth, or 'standard care'. The project was led by the two key research questions:

- How do people with mild stroke and their key support persons experience their transition home from acute hospital care?
- How do people experience the MiStrEnGTH (Mild Stroke Enhancing and Guiding Transition Home) program in comparison to standard care?

4.2 Research Paradigm

The values, beliefs, epistemological and ontological positions that guide a researcher during their studies has a deep impact on the way they approach their research. By the researcher identifying their particular research philosophy, readers can determine how they came to make their findings and the basis of their results (O'Gorman & MacIntosh, 2015). Consequently, this section will involve a discussion in regards to the researcher's ontological and epistemological positions.

4.2.1: Ontological Positioning

Ontology refers to the way researchers understand the nature of the world (Finlay & Ballinger, 2006), and is the study of 'being' and 'reality' (O'Gorman & MacIntosh, 2015). It is a philosophical idea and is focused on what the world comprises, the objects within it and the relationships between those objects (Finlay & Ballinger, 2006). More simplistically, it refers to whether a researcher sees the world as subjective or objective (O'Gorman & MacIntosh, 2015). An objective perspective or 'realist' ontology, identifies that reality is made up of solid objects which can be measured and tested and have a cause-effect relationship with each other (Finlay & Ballinger, 2006; O'Gorman & MacIntosh, 2015). This perspective therefore aligns well with a quantitative research approach. Alternatively, a subjective perspective or 'relativist' ontology is grounded on the fact that reality is made up of the perceptions and interactions of living subjects, and expressed through language (Finlay & Ballinger, 2006; O'Gorman & MacIntosh, 2015). Furthermore, it sees this reality being subject to a myriad of behaviours, attitudes, experiences and interpretations of the researcher and

researched, consequently enabling it to be embraced by qualitative researchers (O'Gorman & MacIntosh, 2015). Based on this, the researcher for this project identified with a relativist ontology and will assume that 'reality' is best explored through the identification of human experiences and the use of words.

4.2.2: Epistemological Positioning

Epistemology can be described as the study of knowledge (O'Gorman & McIntosh, 2015). It determines the way researchers obtain 'valid' knowledge (O'Gorman & MacIntosh, 2015), and how it is interpreted (Finlay & Ballinger, 2006). The epistemological position of a researcher will often determine the type of knowledge they believe research should produce and what is considered adequate evidence in producing that type of knowledge (Green & Thorogood, 2009). The epistemological assumptions of a researcher should therefore align with their ontological positioning (O'Gorman & MacIntosh, 2015).

There are two main positions that exist in regards to epistemology, these being positivism and interpretivism (O'Gorman & MacIntosh, 2015). Positivists maintain that there is one true knowledge and it is able to be gained about the real world through the utilisation of methodological procedures of natural science (Finlay & Ballinger, 2006; O'Gorman & MacIntosh, 2015). Thereby, as knowledge increases in particular fields about particular phenomena, progress towards the 'truth' is achieved (Green & Thorogood, 2009). It also highlights that researchers must utilise the same sort of methods to achieve their results and that all research should be objective, rational and neutral (Finlay & Ballinger, 2006; Green & Thorogood, 2009). This epistemological position is therefore popular amongst quantitative researchers (Finlay & Ballinger, 2006) and aligns with a realist ontology.

Alternatively, researchers that have a relativist ontology and utilise qualitative methodologies tend to adopt an interpretivist epistemology (Green & Thorogood, 2009). Interpretivism seeks to identify trends in relation to a certain phenomena, rather than 'truths' (O'Gorman & McIntosh, 2015). It considers multiple realities from different individuals, the context of the phenomenon being researched, the context in which understanding and interpretation occurs, and the depth of the researcher's involvement (O'Gorman & McIntosh, 2015). Interpretivism enforces that it is impossible for a researcher to remain objective due to the fact that their identity and standpoint shape the research process and findings (Finlay & Ballinger, 2006). This means that findings from interpretivist research remain provisional and are dependent on contextual factors (Finlay & Ballinger, 2006; O'Gorman & McIntosh, 2015). Due to the nature of

the topic being investigated in this research project and the qualitative methodologies employed, the researcher identified with an interpretivist epistemology.

4.3 Research Design

As stated in the previous section, this thesis reports on a project that is embedded within a larger randomised controlled trial (RCT). The RCT aimed to explore the efficacy of MiStrEnGTH, a novel allied-health led, stroke specific self-management program in comparison to standard care, from a quantitative perspective. The current thesis focuses on investigating the experience of participants who partake in either MiStrEnGTH or standard care during the RCT, as well as their overall transitional experiences following mild stroke from a qualitative perspective. A phenomenological approach was chosen over other qualitative approaches due to the research questions aiming to explore an experience or "phenomenon". An interpretative phenomenological analysis (IPA) design was deemed to be the most appropriate phenomenological approach as the aim of the thesis was to provide an in-depth exploration over time, which IPA enables through the use of smaller samples. IPA aims to capture the 'essence' of major life experiences (Smith et al., 2009) and identifies how people make sense of their experiences, including major transitions (Smith et al, 2009). Alternative phenomenological approaches, such as descriptive phenomenology were considered; however, were deemed to not provide the level of interpretation desired due to the focus on providing concrete descriptions of experience. The remainder of this chapter will provide an in-depth description of IPA, followed by the author's reflexivity which is a vital part of IPA, the methodology of the research, and the methods adopted to achieve methodological rigour.

4.3.1 Interpretative Phenomenological Analysis (IPA)

IPA is an approach to qualitative analysis that aims to explore people's perceptions and experiences of the world (Finlay, 2011; Finlay & Ballinger, 2006; Green & Thorogood, 2009; Smith & Osborn, 2008). It is therefore derived from phenomenology and hermeneutics, in that it is concerned with the study of experiences but acknowledges the interpretation that occurs during the data analysis (Smith et al., 2009). The perceptions and experiences that are the focus of IPA occur within a certain situation of interest, be it illness, transition or life event (Finlay, 2011; Smith & Osborn, 2008). It is idiographic in its approach, as it aims to deeply explore the essence of each individual's experience and their perception of it (Finlay, 2011; Finlay & Ballinger, 2006; Smith & Osborn, 2008). In stating this, it is not opposed to more general claims for larger collections of individuals, however places emphasis on analysing individual cases before making generalisations (Smith et al, 2009; Smith & Osborn, 2008). Whilst exploring the individual's experience, focus is given to their cognitive, linguistic, affective and physical being (Finlay & Ballinger, 2006; Smith & Osborn,

2008) assuming that a person's statements, their thoughts and their emotional states are all connected (Smith & Osborn, 2008). Due to this heightened focus on individual experiences, IPA has been indicated as a good method of inquiry for researchers exploring the lived experience of individuals undergoing care (Finlay & Ballinger, 2006).

The methodology of IPA will be discussed later in this chapter, however broadly IPA involves a two-stage interpretation process as the researcher attempts to make sense of the individual's sense-making (Finlay & Ballinger, 2006). Due to the high level of interpretation that is implicit in IPA, the important role and influence of the researcher is identified and considered when reporting results (Finlay & Ballinger, 2006; Smith, 2006; Smith & Osborn, 2008). Whilst acknowledging the role of the researcher, the IPA approach also enforces the participant as a sense-making creature and their role in interpreting the phenomenon of interest (Finlay, 2011; Smith & Osborn, 2008). Finally, the impact of the interaction that takes place between the participant, the researcher and their interpretations is recognized (Finlay, 2011). In order to complete this interpretation process, IPA has been associated with a practical, systematic approach to its methodology, positioning it favourably amongst qualitative researchers (Finlay & Ballinger, 2006; Finlay, 2011). Researchers are often able to discuss results with more confidence by using such a systematic approach to qualitative research, enabling strong contributions to the healthcare system knowledge base (Finlay, 2011).

4.3.1.1 Role of Reflexive Practice in IPA

IPA, as an approach, has a strong emphasis on exploring personal perspectives of experiences, whilst also acknowledging the interpretative process that is involved in qualitative research (Smith et al., 2009). For instance, as researchers are unable to extract experiences directly from the minds of people, they are forced to interpret what the person has said to them (Smith & Shinebourne, 2012). This is defined as a 'double-hermeneutic', the process of which is outlined in paragraph two of 4.3.1 (Smith & Shinebourne, 2012). It is because of this integral role that the researcher plays in the IPA process that it becomes important to undertake reflexive practice.

Reflexivity is a measure of credibility, trustworthiness and non-exploitative research (Berger, 2015). It is a strategy which involves the use of self-appraisal in research and recognising the effect that the researcher has on the research (Berger, 2015). This can take many forms and may include the researcher being aware of their effect on: the selection of the setting and people that are studied, the questions asked, the data collected, and the interpretation of data (Berger, 2015). Researchers must therefore examine their own biases, beliefs, values, assumptions, interests and personal experiences, before, during and after conducting research (Berger, 2015; Carpenter, 2010).

Factors such as: gender, age, affiliation, race, sexual orientation, immigration status, personal experiences, linguistic tradition, beliefs, biases, preferences, theoretical, political and ideological stances; should all be taken under consideration when conducting IPA research in order to identify the researcher's impact on procedures and findings (Berger, 2015). The use of first-person language is used to demonstrate reflexivity (Berger, 2015) therefore the next section strays from the writing style of the rest of the thesis in order to ensure that it is completed in a methodologically appropriate manner.

4.3.1.2 Personal Reflection

My background is not one that is heavily beset with adversity and it must be acknowledged that I have lived a relatively privileged life, which may have affected the topics that I researched during my thesis, the way I interacted with participants and my interpretation of results. I am a Caucasian, heterosexual woman in my mid-twenties, who was born in Australia in a small country town to very loving parents. I grew up with Christian beliefs however, in my late teens made the decision to live my life agnostically. I went to a privately-funded high school where people were of a higher economic income. I was raised though to be sensitive to people's emotions and always behave in a morally correct manner, whether it be in matters relating to the environment, people or law. I therefore developed a strong desire to assist those in need, especially those that were unwell, leading to my study of occupational therapy and an interest in stroke. Upon commencing my thesis, I had worked as an occupational therapist for under two years. Within this time, I had worked as a community occupational therapist, errorless learning therapist with people with traumatic brain injuries, and as an occupational therapy research assistant. Whilst none of these positions specifically worked with people with stroke, I maintained a desire to work in the stroke field from my undergraduate studies.

My background, as described above, may have had an effect on a number of elements of the research process. Firstly, during the design stage of the project, the questions I steered towards may have been less confrontational than those from more adverse backgrounds. To combat any personal bias, I did undertake an extensive literature review and reflect with my supervisors on the most pertinent questions to ask people with mild stroke. Secondly, at the data collection stage, my participants may have judged my personal appearance and professional background in order to decide whether I would be empathetic to their stories, therefore determining the amount that they were willing to reveal about themselves and their journey (Berger, 2015). I tried my utmost to develop rapport before starting interviews in order to combat this; however, certain elements could not be altered, such as my gender. This may, for instance, have impacted male participants and their

willingness to reveal more intimate, personal details (Berger, 2015). Further, most of my understanding about mild stroke and the experiences people have after such an event has come from a scholarly perspective; however, as neither I nor any members of my family have experienced a stroke, I am ignorant from a personal perspective. This may have enabled my participants to feel more empowered as they may have viewed themselves as the 'expert' on the topic (Berger, 2015). The downside of this ignorance, however is that it may have meant that I was not able to fully comprehend the experiences of participants without personally experiencing a mild stroke myself. I believe that my ability to empathise has developed through other life experiences though, for instance living with an emotionally unstable sibling and losing a parent to cancer, which have enabled me to develop an ability to comprehend what others might be experiencing or feeling during adverse circumstances.

During data analysis my background may have played a part in which data I gave more emphasis to. For instance, my interest and awareness of people's emotions may have meant that I paid more attention to emotive data extracts instead of ones that described more physical or cognitive issues. Further, my clinical background as an occupational therapist definitely played a role in the way that I viewed the data and how I looked for the way people experienced their meaningful occupations. To combat this I incorporated a number of reflexive strategies that are described in detail in the next section.

In addition to the above personal reflection, it must also be taken into consideration that this thesis was embedded within a RCT and this may have impacted the way I viewed the data. For instance, MiStrEnGTH was an intervention developed by my supervisors and whilst methods were incorporated to reduce the chance of bias, there may have been a subconscious desire to view the program more favourably.

4.3.1.3 Incorporation of Reflexivity Throughout Thesis

Reflexivity was incorporated at the development, data collection, data analyses and write-up phases of my research project. During the development of my research project, as mentioned above, I discussed with my supervisors my intentions for the project and research questions. This gave an opportunity for them to identify any personal biases that may be directing my research project. During data collection, as well as the reflective practices mentioned above, I also completed member checking. This occurred at the end of each interview where I summarised my understandings of participants' responses and reported these back to the participant to allow them to rectify any misinterpretations. A further reflexive strategy that was undertaken during data collection was prolonged engagement and repeated interviews with the same participants. In two

out of three of the studies, repeated interviews were conducted over a 6- to 9- month timeframe which allowed me to reflect on my role in interviews and alter the way I asked questions in subsequent interviews if I thought I had been leading or biased in any way.

When completing data analysis and reporting, reflection was undertaken to ensure that unconscious editing did not occur and findings were a true reflection of the data (Berger, 2015). This included taking time between different analysis periods to reflect on emerging themes and determine whether any personal influence had contributed to them (Berger, 2015). Further, discussions were undertaken with my supervision team to ensure that personal bias was not overtaking data analysis (Berger, 2015). All discussions and decisions were also documented and sent to all members of the research team to ensure an audit trail was developed (Berger, 2015).

4.4 Study Outline & Justification

4.4.1 Study 1: Spousal Dyad Case Study of Mild Stroke and MiStrEnGTH Experience

The purpose of this study was to thoroughly investigate and understand the transitional experience of living with a mild stroke, within the context of a spousal dyad and the MiStrEnGTH program. A case study approach was decided upon due to its ability to follow the case for a longitudinal time period, obtaining data at multiple time points, resulting in an ability to examine the pattern of change throughout the transition period (Nock, Michel & Photos, 2007; Yin, 2014). In this particular study, data was obtained at 1-, 3-, 6- and 9- months post discharge, to ensure a substantial time period of transition was covered, including post intervention, whilst also enabling minor changes to be detected. Furthermore, this approach allowed for a much greater level of detail in comparison to larger group research designs, enabling connections and comparisons to be made within the single case study (Nock et al, 2007; Smith et al, 2009).

4.4.2 Study 2: IPA Study Exploring the Mild Stroke Experience

A broader IPA comparative study aimed to involve three participants from both the MiStrEnGTH and ‘standard care’ arms of the study and collected data at 1-, 3- and 6- months post discharge. This study aimed to build on and solidify the findings from the first study, allowing for further transferability of results due to the additional cases involved. For feasibility reasons this study focused solely on the time period that the intervention was being undertaken and only included people with mild stroke, to enable a number of cases with rich data to be completed. This study also aimed to reveal what the essence of the transitional experiences is in light of differing socio-economic statuses, social situations, life stages and living environments.

4.4.3 Study 3: IPA Study of Healthcare Experiences of People with Mild Stroke

This study used the same participants as Study 2, interviewed at the same times; however, the focus of data analyses was different. It aimed to further investigate people with mild strokes' perceptions and experiences of stroke-related healthcare services, inclusive of the MiStrEnGTH program and 'standard care'. It aimed to do this along the transitional period in order to identify where gaps may occur along the stroke-care continuum for this population. Furthermore, by comparing the experiences of people who received the two different models of care, the study aimed to identify whether MiStrEnGTH was perceived positively and whether it aided in supporting people with mild stroke during their transition back to the community.

4.4.4 IPA study of the Key Support Persons Experiences after Mild Stroke

This study aimed to explore the key support person's perspective of the person with stroke's transition from acute hospital discharge to home. It originally strived to involve eight participants at one data collection time-point of 9 months post discharge. The study was retrospective, however the purpose of findings was to support and extend results from study one, allowing for different perspectives to be discovered.

4.5 Participants

Study samples within IPA research tend to be smaller in number (Smith et al, 2009), however, the final sample size depends on a number of factors (Finlay & Ballinger, 2006; Smith & Osborn, 2008). For instance, everyday contextual constraints, such as time availability and a focus on rich individual accounts can reduce the number of participants a researcher is able to include (Smith et al, 2009; Smith & Osborn, 2008). Overall though, IPA researchers generally aim to create a well-defined, homogeneous sample which is purposively selected to enable the deep investigation of a particular experience (Finlay & Ballinger, 2006; Smith & Osborn 2008). The homogeneity of the sample may, in some cases, be defined by the rarity of the topic and population; however, in other circumstances where the topic in question is less rare, parameters on demographic details may need to be developed (Smith & Osborn, 2008). Suggested numbers for study samples vary, with authors suggesting one (Finlay, 2011), three to six (Finlay, 2011; Smith & Osborn, 2008), eight to ten (Back, Gustafsson, Larsson, & Bertero, 2011; Fox, Larkin, & Leung, 2011; Nunnerley, Hay-Smith, & Dean, 2013), or 15 or more participants (Smith & Osborn, 2008). The recommended number for a new IPA researcher or student project ranges from three to five participants; however, this number generally increases in doctoral studies (Finlay, 2011; Smith & Osborn, 2008). Smith and colleagues (2009) suggest a tiered approach to a doctoral study with a detailed case study of one participant leading the study, followed by a broader study of three participants and a large study of eight

participants. This tiered approach was utilised in this research project with modifications to allow data to be collected from both people with stroke and key support people, and to answer the research questions.

The aim was to conduct three studies – a detailed case study of one spousal dyad (MiStrEnGTH), followed by an in-depth comparison between three people with stroke from each treatment type (six in total), and finally a broad exploration of key support person experiences including eight key support persons (four MiStrEnGTH and four standard care). Due to recruitment for this project occurring at a later stage of the RCT's these numbers were not able to be achieved. Consequently, the current research project recruited one spousal dyad for an in-depth case study (MiStrEnGTH), and an in-depth comparison between five cases (three from 'standard care', and two from MiStrEnGTH, including the participant from the in-depth case study), and four key support persons (2 MiStrEnGTH and 2 Standard Care).

All participants were recruited from the Metro North Hospital and Health Service (MNHHS), Queensland, Australia. Treating teams in this hospital and health service identified potential participants and notified the research team. Inclusion and exclusion information for participants is outlined below.

4.5.1 Participants with Stroke

All patients aged 18+ years of age admitted to a MNHHS facility with an acute mild stroke were considered for inclusion in the study. Additional inclusion criteria were: admitted for management of an acute mild stroke, receipt of acute stroke management only (i.e. not admitted to the inpatient rehabilitation ward), discharge destination of a home or community environment, and adequate language and cognition to provide consent and complete outcome measures/interviews. Exclusion criteria included: discharge to a residential care or other healthcare facility, and existing comorbidities limiting participation in a rehabilitation service (e.g. dementia or severe mental illness).

4.5.2 Key Support Persons

A key support person was identified (where possible) by participating patients with stroke and invited to participate in the study. Key support people were either close family members or friends who were identified as being there to support the person with mild stroke in the first 6 months after the stroke event. Inclusion criteria for key support persons included: adequate language and cognition to provide informed consent, the responsibility of providing informal assistance that is

ongoing or likely to be ongoing in terms of support or supervision of the participant with mild stroke, and aged over 18 years.

4.6 Recruitment Process

As stated above, participants were recruited from the MNHHS. Treating staff at the MNHHS stroke services were informed of the trial and participant requirements. Consequently, they identified potential participants and notified the research team. The project site manager then provided information sheets to potential participants and collected informed consent from participants with stroke and their key support persons (where identified and applicable), through signed consent forms. At this point, the project site manager also recorded complete demographic data from the participants' hospital records, including: age, gender, date and type of stroke, site of lesion, neurological deficit, and disability level (modified Rankin Scale). Data collected in relation to key support persons at this point included: age, gender, relationship to client, and employment status. Additionally, 10cm visual analogue scale (VAS) scores were taken for people with mild stroke and key support people in regard to satisfaction with services. Participants were given the choice to consent to participation in both the quantitative and qualitative components of the study or just the quantitative component. Participants who consented to being approached for interviews were contacted and consecutively recruited by the doctoral candidate (TH). The recruitment period for the RCT occurred between January 2016 and June 2017. The recruitment and data collection period for the series of qualitative studies included in this doctoral program occurred over an 8-month period, between November 2016 and June 2017.

4.7 Intervention

4.7.1 'Standard Care'

This group consisted of participants who received usual care from the participating hospital at the point of discharge. This type of care was provided by the participant's treating team and may have comprised some or all of the following: stroke education, often provided by an allied health professional or stroke nurse, referral to a general practitioner (GP) and a discharge report, referral to an outpatient clinic follow-up appointment at 1-3 months post discharge, provision of information regarding peer support groups targeted at people with mild stroke/stroke, and a referral to and information regarding local community-based programs and services.

4.7.2 MiStrEnGTH

MiStrEnGTH was a stroke specific self-management program (SSMP) that used a telehealth approach (in the form of a telephone call) to assist individuals with their transition home after experiencing a mild stroke. The program aimed to enable people with mild stroke to: manage their

symptoms, address physical and psychosocial difficulties, meet rehabilitation needs, and improve their lifestyle. Although each session followed a set format, the program was tailored to each participant's individual needs.

MiStrEnGTH was delivered through telephone calls during the initial 6 months post-discharge from hospital. Participants received a maximum of five consultations that occurred at: 1-week post-discharge, 4- and 8- weeks post-discharge, and two within the 3-6 months post-discharge, as needed and identified by the participant or their key support person. The participant and key support person were provided with the contact details for the 'therapist' should they have needed to contact them in between sessions. MiStrEnGTH participants received the telephone communications on top of 'standard care'. It should also be noted that the therapist in this case was not aware of the study hypotheses or aims.

Format of MiStrEnGTH sessions:

1. Reflection:

The individual with mild stroke was encouraged to reflect on and acknowledge the areas of change in their life since stroke (both good and bad). During this step of the phone conversation, the therapist also had the individual reflect on achievements they had made since the stroke.

2. Management:

The therapist used the National Stroke Foundation Post-Stroke Checklist: Improving Life After Stroke with the individual. This assisted with the identification of areas of life that were impacted since the stroke. After identifying the areas of life that had been impacted, an in-depth discussion occurred around impacted areas, including supports available and unmet needs.

3. Goal Planning:

Goal planning was guided by information obtained from the Reflection and Management steps of the phone consultation with long term goals developed for the participant during the initial phone consultation. The Scobbie, Dixon and Wyke's (2011) framework was utilised to assist with emphasising the importance of the motivational and action phases of the goal planning process. The motivation phase consisted of identifying priority goals and breaking them down into specific, attainable targets. The action phase utilised a problem-solving approach to determine what was going to be done, how, when and by whom in order to achieve the targets. During this phase strategies to overcome hurdles were also developed, and outcome reporting completed. The goal planning step of the consultation also ensured that participants and key support persons (if the participant identified one) learned how to develop their own goals and the action plans to work towards them.

4. Education:

This step of the telephone consultation involved discussion about how to access relevant information for the participant that targeted their individual needs. The therapist was able to provide a brief verbal education session; however, they also discussed means for obtaining education on stroke-related topics through other available sources (e.g. internet, support groups etc.) to promote self-management.

4.8 Data Collection

Whilst IPA provides room for a number of different data collection methods, semi-structured interviews tend to be the preferred avenue, with other methods such as field notes used as supplementation (Finlay & Ballinger, 2006; Finlay, 2011; Nunnerley et al., 2013; Smith & Osborn, 2008). The semi-structured interviews used in IPA research generally use exploratory questions that are open-ended and focus on the meaning of experiences (Finlay, 2011). They allow the participant to provide a rich account and there is flexibility for questions to be altered to explore areas of interest (Finlay, 2011; Smith & Osborn, 2008). Questions explored in an IPA study are guided by a semi-structured interview schedule. The current study utilised Smith and Osborn's (2008) suggested outline for creating an interview schedule, where the main research questions are investigated through topic areas obtained from reading the literature and determining pertinent issues for the population of interest. Topic areas were put into an appropriate sequence within the interview schedules, with more sensitive topics appearing later, and questions, probes and prompts developed for each topic area (Smith & Osborn, 2008). The interview schedules for this research project can be viewed in Appendixes 1 (pp.201-202) and 2 (pp.203-204), however, a brief description of topic areas explored is presented below.

Topic areas covered in these interviews included: engagement in meaningful activity (including leisure, work and home-life), community participation, quality of life, mood, driving, personal relationships, lifestyle changes and satisfaction with care received. Key support person interviews included the following topic areas: relationship with participant with stroke, changes in home environment since the participant with stroke had returned, changes in roles and satisfaction with care.

All qualitative interviews were conducted by the same member of the research team, who was not blind to group allocation or aims of the study. All interviews were audio recorded (with consent) and transcribed verbatim. Qualitative semi-structured interviews did not have a time-limit attached to them however lasted for between 17 and 94 minutes. Qualitative interviews were completed in participants' homes and participants with stroke and key support persons were

interviewed separately to allow for free expression. The semi-structured interviews were completed at approximately 1-, 3-, 6- and 9- months post-discharge depending on the individual qualitative study. Verbal summaries were provided at the end of each interview and repeated at the start of any additional interviews to ensure the candidate's interpretations were in line with participants' views.

4.9 Data Analyses

As stated previously, an IPA approach was utilised for the analyses of qualitative data. IPA is iterative, inductive and emergent, and uses a systematic approach which focuses on individual meanings before expanding to more generalised findings (Finlay, 2011; Nunnerley et al., 2013). IPA was therefore completed by the doctoral candidate who read through transcripts multiple times to familiarise herself with the data (Back et al, 2011; Finlay, 2011; Nunnerly et al. 2013). After this initial familiarisation, the doctoral candidate then coded transcripts, using line-by-line coding strategies, where initial interpretative comments were noted in the left-hand side column of the transcripts (Back et al, 2011; Finlay & Ballinger, 2006; Smith et al, 2009). A key was then developed to correspond with emerging themes, with each theme being allocated a colour, with this colour being utilised for a second round of analyses. Finally, connections were made between the emergent themes leading to the development of overarching themes (Finlay, 2011; Smith et al, 2009) and these were given a final check by the doctoral candidate during each individual study.

One of the doctoral candidate's supervisors (Professor Louise Gustafsson) cross-checked themes, ensuring that they were representative of the raw data. Associate Professor Petrea Cornwell assisted the doctoral candidate and Professor Louise Gustafsson during iterative discussions in order to further formulate themes. Member checking also occurred to ensure qualitative results were representative of the participants' experiences and views, see 4.3.1.3 for details. It should be noted however, that whilst member-checking was completed, IPA does acknowledge that there will inevitably be a level of interpretation completed by the researcher (Smith et al., 2009). After all feedback was obtained and iterative discussions had occurred between all members of the research team a final list of themes was produced for each of the studies. These themes consequently produced the 'essence' of the transition to home and/or MiStrEnGTH experience (Smith et al, 2009).

The development of themes occurred slightly differently in the first study in comparison to the final two studies. For Study 1, each transcript was viewed afresh to identify themes and then themes identified were compared between manuscripts across timepoints and participants (Back et al, 2011; Finlay & Ballinger, 2006; Finlay, 2011; Fox et al, 2011; Smith et al, 2009). For all other studies, themes identified in the first manuscript or set of manuscripts (when participants are

interviewed at more than one time point), were used in subsequent manuscripts; however, as novel themes were identified in subsequent manuscripts these were also noted (Fox et al, 2011; Smith & Osborn, 2008). This difference in analysis occurred due to the first study being aimed at producing the most in-depth information of all three studies and therefore closer attention was paid to the detail of each individual transcript.

Demographic Data & Triangulation: Quantitative data was used purely for descriptive purposes. Results obtained from quantitative analyses methods was used for triangulation and comparison with qualitative results in the third results article, *see Chapter 7*.

4.10 Qualitative Methodological Rigour

How best to address methodological rigour within qualitative research is yet to be solidified (Tobin & Begley, 2004). This uncertainty results from the lack of cohesion between philosophical paradigms and technical methodological requirements (Tobin & Begley, 2004). For instance, because of the extensive use of quantitative research strategies the language used within the quantitative paradigm has become the accepted universal language for research methodology, rather than it being used solely for quantitative research (Tobin & Begley, 2004). The values, beliefs, epistemology and ontology of the quantitative and qualitative paradigms differ however, which may result in semantic incompatibility (Tobin & Begley, 2004). For this reason, this section will introduce current concepts used in qualitative research for assessing methodological rigour, and will state how these were achieved in this thesis.

4.10.1 Trustworthiness

Qualitative researchers have started to use the term 'trustworthiness' in favour of the quantitative concept of internal validity (Tobin & Begley, 2004). Whilst a number of features are said to contribute to trustworthiness within qualitative research, Polkinghorne (1983) states that four main qualities demonstrate trustworthiness. These features are vividness, accuracy, richness and elegance (Polkinghorne, 1983). Vividness refers to the ability of the research to generate a sense of reality for the reader (Finlay & Ballinger, 2006). When the research presents a phenomenon in such a way that readers are able to recognise it from their own experience or are able to imagine it, the research is said to be accurate (Finlay & Ballinger, 2006). Richness demonstrates the ability of the research to enable the readers to enter it emotionally (Finlay & Ballinger, 2006). Finally, elegance describes the ability of the research to be presented in a graceful, clear and poignant manner (Finlay & Ballinger, 2006). In the current study, attention was paid towards providing thick, clear descriptions that were written in line with what participants had reported and in a manner that enabled readers to develop a clear picture of the phenomenon.

4.10.2 Transferability

Transferability is essentially an extension of trustworthiness (Morehouse, 2012). Transferability is the qualitative alternative to generalizability and refers to the extent to which findings are able to be applied to other settings (Green & Thorogood, 2009). For a study to have good transferability it must be trustworthy, as the description of the phenomenon should be clear and easily pictured in order to determine whether it is applicable to a different context (Green & Thorogood, 2004; Smith et al, 2009). Transferability is the ideal within qualitative research, with the main aim being to achieve purposeful rather than random sampling allowing the research to address specific, rather than 'general' accounts (Green & Thorogood, 2009). Researchers can help in the transferability process by linking their findings to the wider literature and demonstrating how they may shed light within broader contexts (Green & Thorogood, 2004; Smith et al., 2009). Transferability is thus unique in the sense that it is not only the responsibility of the researcher but also the reader, as they must determine whether findings are applicable to their context given the researcher's description (Morehouse, 2012). Therefore, similar to trustworthiness and in order to ensure the current study was transferable, a thick description of the participants and context was provided in each of the results chapters. This was to ensure readers could decipher whether the results were applicable to their context. Furthermore, each study and its findings were linked to the wider literature for the interpretation of the reader.

4.10.3 Reflexivity

Reflexivity is another method that qualitative researchers may utilise to achieve methodological rigour. Reflexivity recognises that research and researchers are part of the world and there is no place which one can occupy that allows for total objectivity in qualitative research (Green and Thorogood, 2009). It accepts that the researcher is a part of the production of data and its interpretations, and aims to consciously reflect on this process (Berger, 2015; Finlay & Ballinger, 2006). It involves critical self-reflection and assessing one's background assumptions, positioning, values, beliefs, interests and behaviour and the way these may impact on the research process, as well as how the research may change each of these (Carpenter, 2010; Finlay & Ballinger, 2006; Green & Thorogood, 2004).

In addition to the reflexive section provided by the doctoral candidate in 4.3.1.2, other specific methods for demonstrating reflexivity are available. Examples include; writing memos (Carpenter, 2010; Finlay & Ballinger, 2006), prolonged engagement in research activities, member checking, triangulation, peer review, forming of peer support networks, and keeping of an audit trail (Ahern, 1999; Berger, 2015; Bradbury-Jones, 2007; Fonow and Cook, 2005; Padgett, 2008; Russel & Kelly,

2002; Smith, 1999). In this program of research, member checking and prolonged engagement with research activities were utilised in order to achieve reflexivity. Each of these are briefly described below.

Member checking is represented through participants being asked to review and comment on study findings (Carpenter, 2010). When utilising member checking, participants can either comment on summaries of their own interviews or on emerging themes of the study (Finlay & Ballinger, 2006). Member checking in this program of research occurred at the end of each interview through a verbal summary to identify whether the researcher's initial interpretations aligned with the participant's. The use of prolonged engagement in research activities was the final approach to ensure reflexivity in this study. This involved the first two studies of the research project being undertaken for a minimum of 6 months, enabling the researcher enough time to ensure that they were aware of how their involvement in the research may have shaped results.

4.11 Chapter Summary

This chapter has outlined the purpose of the research discussed in this thesis and the methodology that was used to achieve this purpose. The research aimed at exploring the essence of the transitional experience for people with mild stroke, and their key support person, from post-acute hospital discharge to home, in the context of two different models of care. The doctoral candidate adopted a relativist ontology and interpretivist epistemology during the research and therefore the research conducted was qualitative in nature. The chapter outlined how the doctoral candidate approached the exploration of this phenomenon through the tiered method suggested by Smith and colleagues (2009). The first level of this approach suggests an in-depth case study. Consequently, the following chapter, being the first results chapter, will discuss findings from a longitudinal case study of a person with mild stroke who received the MiStrEnGTH program and his key support person.

Miss Tenelle Hodson – PhD candidate

Chapter 5: 'Just got to live life as it comes': The longitudinal experience of transitioning to home following a mild stroke for a spousal dyad

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). "Just got to live life as it comes": A case study of the spousal-dyad longitudinal mild stroke transitional experience. *Brain Injury, 33*(9). doi:10.1080/02699052.2019.1629625

This chapter explores the experience of returning home from acute hospital discharge, following a mild stroke for a couple aged in their mid-60s. This particular couple was chosen due to their characteristics reflecting the average age, gender and marital status for people with mild stroke and their partners. The couple received the MiStrEnGTH program and therefore the essence of the phenomenon captured in this chapter is framed within the context of receiving this novel mild stroke health service. The couple was interviewed at four different time points: 1-, 3-, 6- and 9-months post discharge demonstrating a longitudinal view of the experience. Two main themes were identified in the study, 'The unexpected, undesirable, and short-lived' and 'The new normal', reflecting the two essential experiences of the phenomenon. Following the presentation of findings in this chapter a discussion is presented that links findings to the wider literature enabling the reader to transfer them to the broader mild stroke population.

The PhD candidate was primarily responsible for the design of this study, data collection and analyses, and writing of the article. Professor Louise Gustafsson contributed substantially to the article, assisting with data analyses, ensuring that all codes and themes were reflective of the raw data, and providing critical appraisal to writing. Associate Professor Petrea Cornwell participated in iterative discussions with the PhD candidate and Professor Louise Gustafsson and provided critical appraisal to writing.

Contributor	**Statement of contribution**
Tenelle Hodson (candidate)	Conceptualisation of research design and question (70%) Data collection (100%) Data Analysis (70%) Writing and editing of manuscript (70%)
Louise Gustafsson	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (20%) Writing and editing of manuscript (20%)

Miss Tenelle Hodson – PhD candidate

Petrea Cornwell	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (10%) Writing and editing of manuscript (10%)

Miss Tenelle Hodson – PhD candidate

5.1 Abstract

Objective: To longitudinally explore the transition home for a spousal dyad following mild stroke, in the context of a mild stroke-specific health service.

Research Design: A case study approach, using an interpretative phenomenological analysis (IPA), was identified as suitable for this study, as it enabled the essence of the phenomenon to be examined.

Method: Participants were purposively chosen from a randomised control trial (RCT), to reflect the average age, gender and marital status of the mild stroke population. The participants were a male (age 64) and his wife (age 62). Participants received the RCT intervention. Semi-structured interviews were completed separately with participants at 1-, 3-, 6- and 9- months post stroke.

Results: Two themes were identified: (1) The unexpected, undesirable and short-lived, and (2) The new 'normal'. The first theme reflects the confusion, adjustment and adaptation that occurred for the couple, especially during the first month at home. The second represents the couple's journey back to their everyday lives following hospital discharge, but also the questions and changes that remained present at 9 months post-discharge.

Conclusions: Themes demonstrate an ongoing process of adjustment and the contextual nature of the transitional experience. Results also indicate the need to ensure that individuals have access to mild stroke specific information across the transition continuum.

5.2 Introduction

The high level of independence observed after a mild stroke frequently results in a swift hospital discharge (Green & King, 2010). However, the term 'mild' underplays the significance of the event (Green, 2007). Whilst the classification of mild stroke varies, it is generally acknowledged that people who are able to mobilise and communicate, as well as complete activities of daily living independently are considered to have had a 'mild' stroke (Green, 2007; Wolf et al., 2011). Regardless, people with mild stroke can experience difficulties in returning to a number of areas of daily life (Adamit et al., 2015; Carlsson et al., 2009; Green & King, 2007;2010; Kristensen et al., 2014; Wolf et al., 2011). Further, the lives of loved ones are impacted as they attempt to adjust to, and compensate for the difficulties that the person with mild stroke experiences (Green, 2007; Lou et al., 2017; Plank, Mazzoni, & Cavada, 2012).

The ongoing presence of difficulties following mild stroke results in a period of transition (Green, 2007). For people with mild stroke, the transition is an unanticipated one as it occurs as a direct result of the stroke event and cannot be predicted or prepared for; however, requires the person to change the way they view themselves and their circumstances. (Goodman et al., 2006; Hall et al., 2012). In order for health professionals to assist in this transition, it is vital that an understanding of the lived experience of this phenomenon is developed from the perspective of the person with mild stroke and their spouse. There is currently limited literature exploring the experience of transitioning from acute hospital care to home after a mild stroke, within the context of a spousal dyad (Green & King, 2007). Researchers have started this exploration from the perspective of the early transitional stage, i.e. 1-3 months after discharge (Green, 2007; Lou et al., 2017), however further in-depth, longitudinal research is required as only one such study appears to exist (Green & King, 2009).

Three studies have been identified in the current literature that explore this phenomenon. The first study included 26 Canadian males with mild stroke and their spouses during the first 3-months following hospital discharge, utilising telephone interviews to collect data and conventional content analysis to obtain findings (Green, 2007). This study identified that the impact of mild stroke is multifaceted and the stroke had implications for both individuals in a relationship (Green, 2007). Furthermore, it found that successful adaptation involves re-evaluation of life-plans, reordering of priorities, and incorporation of difficulties into life situations (Green, 2007). Green, then went on to explore this phenomenon with a more longitudinal approach in her study with King (2009). This second study again involved telephone interviews with 26 married couples and conventional content analysis, however, was conducted over 12 months (Green & King, 2009).

From this study two main themes were identified as being dominant over the first 12 months, post hospital discharge: being vulnerable and realisation (Green & King, 2009). A more recent article produced by Lou and colleagues, supported these findings, however their results were slightly more positive, perhaps reflecting the different health context (Lou et al., 2017). Using thematic analysis, the study investigated the first month of the transition to home for 22 people with mild stroke and their partners in the context of early supported discharge (ESD) in Denmark (Lou et al., 2017). Findings demonstrated that: participants felt confident returning home; were assured by their partner's presence; mild stroke impact was contextual; and rehabilitation was a collaborative process (Lou et al., 2017).

Whilst these studies contribute to the understanding of the phenomenon in question, they have limitations to the depth of information that they can provide. For instance, two of the studies (Green, 2007; Lou et al., 2017) did not cover the 'critical' transition period of 6 months identified in acquired brain injury literature (Hall et al., 2012). This period is considered a vital interval of the person with stroke's transition journey as it is the time during which they return home and start to re-engage in daily life, including work, driving and parenting (Hall et al., 2012). Consequently, many changes occur and may be observed during this period which may not have been identified by these studies. Furthermore, the two studies conducted by Green (2007) and Green and King (2009) occurred over the phone and were guided by two open-ended questions derived from questionnaires that were targeted at particular aspects of the post-discharge transitional experience, i.e. quality of life and carer burden. Whilst these areas are valid components of the transition experience and provide scope for further research to be built upon, by concentrating solely on these two elements the data obtained may be restricted. Lou and colleagues' study (2016) also had some limitations in regards to the transferability and depth of information. For instance, the study was conducted within the context of ESD, which for some countries with fewer services over greater geographical areas is not feasible, limiting transferability of results (Lou et al., 2017). Furthermore, couples were interviewed together which may have impacted the openness of discussion (Lou et al., 2017).

Whilst the qualitative research to date has elaborated on the shared experiences of spousal dyads following a mild stroke, a lack of nuanced analyses of this particular phenomenon exists. This is especially so in regards to the 'critical' transition period of the first 6 months post-discharge. It may be argued that conducting a case study, and the consequent attention to detail that it can contribute to research may result in findings that match the complexity of human psychology itself (Smith et al., 2009). When this is combined with qualitative approaches that focus on the intricacies of phenomena, such as interpretative phenomenology, further enhancement of the understanding of

this phenomenon can be achieved (Hsieh & Shannon, 2005). Furthermore, exploring this phenomenon within different contexts, such as different countries and health systems, will provide illumination to differences and shared experiences more broadly. Consequently, the aim of this study was to provide an in-depth exploration of the mild stroke experience of one couple who received a novel health service within the Australian context. Specifically, this research examined the experience of transitioning from acute hospital care to the community following a mild stroke, for a spousal dyad in the first 9 months post-hospital discharge.

5.3 Methods

This research project was guided by an interpretative phenomenological analysis (IPA) and was the first of a program of studies that aimed to explore the transitional experience of returning to home following a mild stroke (Smith et al., 2009). The research program was guided by a tiered approached outlined by Smith and colleagues, with the initial study suggested to be a case study (Smith et al., 2009), therefore forming the basis of the current study. The studies that follow this one incorporate more participants and take a broader view of the phenomenon, whilst the current study focuses on a more detailed, intricate exploration. The study was embedded within a randomised controlled trial (RCT) that explored the outcomes of a novel stroke-specific self-management program (MIld STRoke ENhancing and Guiding Transition Home [MiStrEnGTH]) versus usual care. The study was approved by the ethics committees of the relevant hospital and health service and universities involved in the study (Approval numbers: HREC/15/QPCH/18; 2016000021; GU: 2015/884). Each participant provided informed consent, and privacy and confidentially rules were strictly abided by, including the de-identification of all transcripts and the use of pseudonyms in reporting results.

5.3.1 Participants

The participants were purposively recruited from the RCT in which this study was embedded. The couple in this study were purposively chosen to reflect the average age, sex (Adamit et al., 2015; Dong et al., 2012; Jacquin et al., 2014; Seymour & Wolf, 2014), and relationship status (Seymour & Wolf, 2014) of the mild stroke population. The chosen participants were therefore a 64 year old gentlemen (Brian) with mild stroke, and his 62 year old wife (Joan). The selected participants were from a large Australian capital city and received the intervention of the RCT.

To be included in the RCT, people with mild stroke had to: (1) be aged ≥18 years, (2) have received hospital care only, (3) have a discharge destination of home/community, and (4) have adequate language and cognition to provide consent and complete outcome measures, including interviews. Key support people were included in the study if they: (1) had adequate language and

cognition to provide informed consent, (2) were responsible for providing informal assistance for the person with mild stroke, and (3) were aged ≥18 years.

5.3.2 Data Collection

Data were collected using semi-structured interviews, guided by an interview schedule. The semi-structured interviews for the person with mild stroke were guided by two open-ended questions: 'tell me about your experience of returning home after having a stroke,' and 'how has your experience been with health services?' Probes, derived from the authors' search of the literature were also used to ensure all aspects of the person's transitional experience were covered and included the following areas: engagement in meaningful activity, community participation, quality of life, mood, driving, personal relationships, lifestyle factors and satisfaction with care. Similar open-ended questions were used for the key support person, including: 'tell me about how you perceive the stroke affected [partner]'; 'can you tell me a bit about how [partner] having the stroke affected your daily life?'; and 'how has your experience been with health services?'. Probes for the key support person, included: the couple's relationship, the home environment, roles within the household and satisfaction with care.

Semi-structured interviews were completed at approximately 1-, 3-, 6- and 9- months post hospital discharge (December 2016-August 2017). All interviews were completed by the lead qualitative researcher (TH). Each of the participants were interviewed separately to allow for openness in communication. Interviews occurred on the same day and participants were given the choice of interview order during each session, with interviews occurring one after the other. The same interview guide was used at each interview time-point; however, each subsequent interview began with a reflection from the previous one, as a form of member checking to ensure interpretations were in line with participants' thoughts. Similar member checking also occurred at the end of each interview. Interviews were conducted within the participants' home and lasted between 28 and 90 minutes. Interviews were digitally recorded with consent and transcribed verbatim.

5.3.3 Data Analysis

The research data were analysed using an IPA approach (Smith et al., 2009). The first stage of this approach involved TH reading through the transcripts multiple times to become familiar with the data (Finlay, 2011). Following this initial stage, TH began the first round of coding where initial interpretative comments were placed beside the data (Finlay, 2011; Smith et al., 2009). Coding was conducted separately for each transcript, with comparisons being made between each time point in regard to how the codes were presented. TH then made links between these initial comments to

develop preliminary themes. Themes were then discussed by all members of the research team and a second round of coding occurred by two researchers using these themes (LG & TH) (Finlay, 2011; Smith et al., 2009; Smith & Osborn, 2008). Following this coding round, preliminary themes were discussed further by all members of the research team and condensed into two themes (Finlay, 2011; Smith et al., 2009). A final round of coding was completed by TH to ensure that all data was represented by the themes.

5.4 Results

5.4.1 Participants & Context

The participants in this study were in their early to mid sixties, Caucasian and of a middle income socioeconomic status. Prior to the stroke, both participants were relatively healthy, however Brian had a history of lung issues and high blood pressure. At the time of the stroke Brian was working full-time in a sales position, and his job monopolised most of his time during the week. He had held this job for a number of years and had been quite successful. During his free-time Brian would complete household chores and was not one to 'relax'. Joan had looked after the home and family for the majority of their lives and spent most of her time participating in household tasks. The couple spent most weekends at their holiday home, where Joan would help look after an older family member who lived in the same town. Brian would often do outdoor activities during these weekends, such as kayaking and stand-up paddle boarding. The couple had four grown children, all of whom had successful careers and their own families, inclusive of four grandchildren living in various locations within Australia. One son was a health professional. The couple also had a small, but close group of friends.

After a hospital length of stay of 5 days, Brian was discharged and received the MiStrEnGTH program. This program was tailored to people with mild stroke and was in addition to the standard practice of the healthcare system in Brian's location. MiStrEnGTH involved an experienced allied health professional contacting Brian five times over the first 6 months after hospital discharge. During these phone calls, Brian would receive a self-management program, where he was given a space to: reflect and identify areas of change since the stroke, create future goals and strategies to achieve these goals, and determine how best to obtain necessary information.

5.4.2 Qualitative Findings

Findings from this study reflect the essence of the journey that was undertaken by the couple in the 9 months following acute hospital discharge. The results also highlight the dynamic that occurred between them during this time. It emerged that for this couple they experienced two phases of their transition, with one occurring in the early weeks following the mild stroke and the second occurring

after this. These two phases are representative of the two themes, which have been titled: (1) *The unexpected, undesirable and short-lived,* and (2) *The new 'normal'.*

5.4.2.1 The unexpected, undesirable and short-lived

This theme represents the first month at home following the mild stroke. It embodies a sense of confusion, adjustment and adaptation, and highlights the couple's attempts at coping with the mild stroke and its repercussions. Whilst these experiences were short-lived, they warrant exploration due to the implications they had for the couple during this period of time. The difficulties experienced were more outwardly expressed by Joan, with Brian only indicating a few areas of disruption. The dynamic that occurred between the couple during this time is revealed by this interplay, with Brian underplaying the significance of the situation and attempting to maintain a sense of 'normalcy' and independence, whilst Joan was more sensitive to the difficulties experienced.

The occurrence of the stroke itself was a shock for the couple and was the triggering event igniting the need for adjustment. In order to adapt to the shock of the event and the changes that followed, they seemed to adopt a 'day by day' approach. This adaptive approach seemed to act as a protection for them during a period of confusion, where the couple were forced to navigate a myriad of information. Joan expressed her feelings of being overwhelmed during this period:

> *'…I think we've been inundated, little bit of information overdrive, if anything and sometimes you sort of got to come back and look at things later and take it all in. I, I felt a bit of information overload in the first couple of days when he was in hospital…'*

Brian's confusion during this time was observed when he discussed the written materials he received. While he was able to identify that he had been given information in regards to his stroke, he was unable to elaborate on the content of the materials or his use of them: *'I've got a folder the size of, with a heap of brochures on everything.'* (Brian). The couple's confusion, however, was improved with the help of their son who was a health professional: *'Um, we had, which was a benefit, our son who could explain it, probably in, in more laymen's terms, some things…'* (Joan).

During the first month post-stroke, it also became apparent that the couple differed in their transitional experience. For Brian, the reduction in activity imposed by medical professionals during this period required adjustment. The need for rest resulted in boredom as he was restricted from doing the occupations that formed his 'normal' daily life. The inability to drive for the first month was particularly difficult: *'…that was the biggest thing, not being able to go and do…want to jump in the car and go anywhere if you had to.'* (Brian). The presence of this restriction led to boundary testing by Brian, particularly in activities that he identified as being part of his household role. A

specific example was given in regards to mowing: *'…which he snuck out and did in the second week, when he was home, it was probably less than two weeks and he only did it 'cause I wasn't here.'* (Joan). Restriction in Brian's activity levels also led to a period of role reversal for the couple, and consequently Joan's daily life was also disrupted. Household tasks that were normally completed by Brian were adopted by Joan and she tended to set aside her own needs in favour of his. Brian's continual presence in the home environment also further altered her daily routine. For instance, Brian would often attempt to do tasks that were incorporated into her day in order to reduce his own boredom. This led to feelings of frustration from Joan:

> *'…he said "I'm just helping" and I said "I know, but". You know, I felt a little bit suffocated sometimes and uh I said "look these are things I do all the time" and, you know, you've. I was trying to impress upon him that he's got to find things to do for himself, not just take over things that I'm doing so that it gives him something to do-'*

Joan also felt that she had to 'entertain' Brian whilst he was at home and be sensitive to any difficulties he was having: *'…it was a bit like having a sick kid at home, you know (laughs) – trying to do things to make them feel better and, and you know, build his strength up, I suppose.'* (Joan). Overall, it was clear that whilst this period did not last long, it did disrupt the couple's daily functioning, resulting in the need for adjustment and adaptation. Furthermore, issues with information provision for people with mild stroke were highlighted, in terms of the ease at which information can be understood and the inefficacy of providing all information at one point in time. This point will be addressed in detail in the discussion.

5.4.2.1 The new 'normal'

A new sense of 'normal' was identifiable for the couple throughout their transitional journey, following the initial shock, confusion, adaptation and adjustment of the first month. This was observed through reiterations of life being *'pretty well the same'*, whilst also acknowledging changes that had occurred, and questions that remained. The changes experienced by each individual were different but both had similar reactions to them. Neither of them portrayed frustration and were quite accepting of changes, reflecting their adaptability and flexibility as a couple. They still, however, outlined questions in regards to stroke repercussions that Brian experienced and these remained present throughout the 9 months of interviews. Overall though, the couple were thankful for a relatively positive outcome following the stroke, which was assisted by their stage of life, social environment and services received.

Both participants stated that most activities of daily living, roles and social dynamics with friends and family remained unchanged. They also however revealed changes in the areas of

awareness of health symptoms, preventative practices, Brian's physical functioning and work. For Joan, the main change appeared to be the adoption of a heightened awareness towards her husband's health. This was not specifically targeted towards stroke related symptoms, but incorporated all aspects of health. This was identified when she spoke of her doctor being unable to provide flu immunisations before going on a cruise: *'-and he said "look, you'll be fine" and I thought "well it was more [husband's name] that I was concerned about.'* (Joan). For Brian, preventative practices became a part of daily life, however these were mostly met with a sense of nonchalance. For instance, medications were viewed as something that just had to be incorporated into the day and he was not too bothered by their presence:

> *'…I was on one tablet before and now I am on four...I was on blood pressure pills before, which I've still got to take one every a morning, which they call preventative. Everything's preventative, I found out, and there's another couple of tablets there. I had one with breakfast, with food, and one at dinner, which is preventative for stroke and then I have one about 9 o'clock at night, which is preventative for cholesterol [laughs].'* (Brian).

Brian also experienced changes relating to physical functioning and the presence of changes in this area resulted in unanswered questions. Throughout the 9 months of interviews Brian's arm and leg experienced sensations of tingling, numbness, being 'weighty', and having 'pins and needles'. Whilst Brian had been given exercises in the acute period by the hospital physiotherapist to address these, no further follow-up had occurred, resulting in the couple questioning whether they were normal or if further intervention was possible. Brian noted that the sensations did not stop him from participating in his usual daily routines, however the ongoing presence of them acted as a reminder of the stroke. In later interviews, both participants appeared to have accepted the presence of the sensations, with Brian stating: *'I think it's always going to be there. Like even at the moment, it's a bit tight.'* A blurring between the symptoms of ageing, previous medical conditions and possible effects of the stroke also became present as time passed. It was clear that Joan in particular was noticing changes that she could not readily distinguish as either a side effect of stroke, a prior condition or a natural ageing process. An example of this related to Brian's apparent fatigue: *'But yeah, like he does get a little bit tireder, but then he's not getting any younger either-'* (Joan).

In regards to work changes, Brian had become more relaxed in his approach. He seemed to have achieved a better work-life balance, depicted when he said:

> *'…whereas once upon a time you'd be up, well I'd be up just after six and start doing paperwork and now I don't. If I get to it, I get to it, so-'.*

Not only did the stroke spark a move towards this balance, but it also meant that retirement became more of a point of discussion. During initial interviews, Brian was quite adamant about retiring and it occurring in his near future, which may have been due to uncertainty of what the impact of the stroke would be. As interviews continued however, the question of retirement became more into a state of ponder:

> *'Like I said to [wife], possibly February, and she says "haha, you said that last year". [Laughs]. We'll just see what happens.'* (Brian).

This hesitance seemed to result from Brian's successful return to work and a fear of how he would fill in his days if he were to retire. Nonetheless, he continued to contemplate his retirement and the stroke seemed to have provided him with the ability to envisage what that might look like.

The ability of the couple to feel 'back to normal' and the reduced impact of the stroke appeared to be assisted by the couple's comparison of Brian's experience with more severe strokes and other health events. Both participants stressed that their situation could have been a lot worse:

> *'And as I said, it was only mild one, where it could have been a hell of a lot worse. There's one poor bugger who was about in his early thirties and he had been there 58 days when I was there.'* (Brian).

By using this comparison, they reframed their situation and took on a perspective that they were 'lucky' and therefore changes that had occurred appeared minimal. This showed their ability to adapt and appraise mild stroke differently, managing the stress that may have come with such an event. Further, in the latter interviews Brian had been diagnosed with a facial cancer and this became his focus during interviews. This highlights the potential for new medical conditions and experiences to override the significance of previous ones.

Finally, the couple's context appeared to ease the impact of the stroke. During the first 6 months of his transition, Brian received the MiStrEnGTH program. This meant that he received extra contact from healthcare professionals to help with self-management, increasing their level of support. The couple also had a long-standing relationship with their general practitioner (GP) and this appeared to provide them with a sense of comfort as they could seek help and guidance from him as questions arose during the transition period. The combination of these factors, and the fact that their son was a health professional, appeared to enable the couple to manifest a faith in their future stroke care if it was ever needed:

> *'…well I've got all the phone numbers of the stroke team and all that inside. Plus there's [GP's name] down the road. Or, or I'd ring my son and say "[son's name], what do you think?"'* (Brian).

Overall, it appeared that the couple had adjusted to the changes that had occurred in their life since the stroke, resulting in a new 'normal'. The way they framed their situation and the presence of certain contextual factors were core to this experience.

5.5 Discussion

This study aimed to longitudinally explore the essence of transitioning from acute hospital care to home after experiencing a mild stroke for one couple, within the context of a novel mild stroke specific health service. Through following this couple's journey, two key themes were identified that reveal this phenomenon and the particularities of it. Whilst it appeared that this particular couple's journey fell naturally into two different phases, it must be acknowledged that further phases of transition may have occurred beyond 9 months post-discharge. Moreover, other people with mild stroke and their spouses may experience additional phases of transition and these may not be linear. This discussion will explore the couple's circumstances in order to enable the identification of potential influences on their transition journey. By doing this, it is hoped that readers will be able to transfer results to other people and contexts. The discussion will then turn to the identified themes and consider these within the mild stroke literature and how they can be extended beyond this couple.

The participants' context played a significant role in their transitional experience. Previous literature has stated that when couples are faced with a stressor event, the interaction of the event with the couple's resources, and how they then define the event contributes to its impact (Olson et al., 1989). The current study reflected this concept as the couple had a number of resources working in their favour. Firstly, they were comfortable in their financial position, reducing concerns associated with healthcare costs and loss of income. Similarly, they were at a stage in life where they had no dependents and were close to retirement age. Consequently, the person with stroke was able to take leave from work, with reduced concern that he would lose his job, and the key support person was able to devote her full attention to him. Finally, the relationship that the couple had with their GP, and the fact that their son was a health professional, are particularly worthy of discussion. It has been identified that within the Australian context, people who have a regular GP are more likely to maintain health appointments (Britt et al., 2016). This may have therefore resulted in a more positive outcome as the couple may have had more contact with their GP, in addition to discussing concerns with their son, increasing their overall feelings of support. Overall, contextual factors appeared to influence the transitional experience for this spousal dyad and it may be useful for health professionals to consider this when working with other people with mild stroke. Further

research is also needed to determine the impact of a diverse range of contextual factors on this experience.

Whilst they had some differences in their perspectives at the start of their transition, the relationship between the current couple remained steady throughout their journey. Previous research into relationships following mild stroke has identified that this may not always be the case. For instance Carlsson and colleagues (2004) reported an imbalance in relationships following mild stroke resulting in increased conflict, divorce rates and relationship issues. Green's study (2007) further supports this through her finding that the experience of role reversal and role changes can negatively impact the marital relationship. The ability of the current couple to maintain a healthy relationship may have resulted from their adaptability to changing circumstances (Armour, 1995), evidenced in their 'day to day' approach. This supports previous research in the context of families, which has identified that the ability to change is a major factor that distinguishes functional couples from others (Olson et al., 1989). Furthermore, as the couple had been together for an extensive period and had minimal history of relationship strain, they were more likely to have a comfortable relationship and be less conflictual (Olson et al., 1989). Finally, literature surrounding coping and resilience suggests that as the couple had assets and resources within their relationship and environment, as noted in this and the previous paragraph, they had greater capacity to adapt and recover after the mild stroke (Frydenberg, 2017).

The theme of 'The unexpected, undesired and short-lived' aligns with prior findings in regards to the experience of the first month at home for people with mild stroke. This is particularly important as minimal research of this phenomenon had been completed within an Australian context. For instance, the person with mild stroke appeared to struggle with occupying himself and fought to maintain his independence; aligning with Green's (2007) and Green and King's (2009) findings which identified that the stroke event can create tension between self-image and reality. Furthermore, for the key support person, adaptation was required due to the presence of her husband in the home. This was also seen in Green's (2007) and Green and King's (2009) findings, identifying that wives find their husbands' presence in the home reduces their personal space and time. However, unlike Green and King's longitudinal study, the current study found that these findings were only identified in the first month post stroke, rather than throughout the entire transitional period. Overall, the similarities identified in the current study's results and those of Green's, suggests that whilst each person will experience their transition differently, there may be commonalities that occur in the first few weeks at home. Health providers therefore may consider

and discuss such experiences with people with mild stroke in order to prepare them for their transition home.

A new version of 'normal' was experienced by the couple in the 9 months that followed the mild stroke, as they adapted to changes. Particular changes that were acknowledged in the current study, such as the person with stroke's changed approach to work (Carlsson et al., 2009; Green, 2007; Kristensen et al., 2014), the key support person's heightened awareness of her husband's health (Green 2007, Green & King, 2009), and the use of the 'mild' terminology as a protective barrier (Green, 2007) have been supported by previous findings. The current study however, also identified novel elements of this phenomenon and provided a new outlook on the experience. For instance, Green and King (2009) identified the theme 'realisation' as being core to the mild stroke experience where the person starts to become aware of the long-term impact of the condition, the loss of roles, abilities and relationships, and identifies a change in self and relationships. The current study however emphasised that the participants predominantly considered their life 'back to normal', emphasising that each mild stroke is a truly individual condition. Furthermore, results highlighted the impact of new health conditions on people with mild strokes' lives and the attention they give towards the stroke event. Once the current participant experienced a new health condition, it was clear that the mild stroke became less important in his life story. This has implications for secondary preventative behaviours. It might therefore be suggested that health professionals monitor the impact of the 'mild' diagnosis and further health issues on people with mild stroke.

The study also brought to attention the difficulties experienced in relation to information provision for this population. From a transition perspective, it appeared that too much information was provided at the start of the couple's journey, but then limited information was given thereafter. This was portrayed through their feelings of 'information overload' and the unanswered questions in the months that followed in terms of ongoing physical changes. It is the role of health professionals to structure information in a way that can be easily understood by people with stroke (Taule & Råheim, 2014), and this study indicates a need for improvement in this area for people with mild stroke. The best time at which to provide information and the best format to deliver the information across the transition continuum must be considered (Rodgers, Bond, & Curless, 2011). Information should not just be provided as a once off to this population. Instead, health professionals need to target people with mild stroke at different points along the continuum, when issues arise and when reminders for secondary preventative measures are needed (Cameron et al., 2016; Hoffman, McKenna, Herd, & Wearing, 2007; Rodgers et al., 2011; Skidmore et al., 2008).

5.5.1 Methodological Considerations

The current study focused on the transitional experience of one marital couple, in one location, who received a specific health service. For this reason, findings are not generalisable to all people with mild stroke or to other locations and health services. It is hoped, however, that the provision of contextual information and suggestions for practice have reduced the impact of this limitation and increased the transferability of findings. Further, IPA acknowledges the impact of the researcher's values and positioning on their research. Therefore, it must be identified that the results from the current study are based on the interpretations of one researcher. The inclusion of a second researcher during data analysis, as well as the use of member checking with participants, attempted to compensate for this limitation. Finally, due to the professional backgrounds of the researchers involved in the study, little exploration of theories related to coping and adaptation occurred, which may have restricted the questions asked during interviews and discussions around the psychological processes that occur during the transition period.

5.6 Conclusion

The current study provided a longitudinal account of the transition to home following mild stroke, in the context of a spousal dyad and novel mild-stroke specific health service. The study adds to findings currently held in the mild stroke field by revealing intricate details of the mild stroke experience, as exhibited by a spousal dyad. The study provides indication that even in the best circumstances, people with mild stroke experience changes to their lives long after the event has occurred. Furthermore, information provision for the couple in this study was identified as being overwhelming, suggesting that attention needs to be paid to individualising information provision and providing it at relevant times during the entire transition period, as issues arise and the information becomes applicable. Finally, it appeared that this couple adjusted well to changes that became present after the mild stroke, with their context appearing to play a part in this. Consequently, the impact of contextual factors may need to be considered when delivering services, in order to target them more effectively. To do this however, further research is needed to explore different circumstances and contexts.

5.7 Chapter Summary

This chapter has explored the longitudinal transitional experience of a person with mild stroke and their key support person after being discharged from acute hospital care, and within the context of receiving a novel, allied-health, stroke-specific, self-management service. It has demonstrated that two main themes portray the essence of this phenomenon: 'The unexpected, undesirable and short-lived; and 'The new normal'. This study was conducted as the first part of a tiered approach to

exploring phenomenon outlined by Smith and colleagues (2009). Consequently, it utilised a case study approach in order to explore the phenomenon in an in-depth manner; however, this limits the transferability as it is only able to portray the experience within one set of contextual influences. The next chapter will therefore explore the experience of mild stroke, post-acute hospital discharge for people with mild stroke, but will incorporate more individuals to ensure more contextual influences can be incorporated and the essence of the phenomenon can be revealed further.

Miss Tenelle Hodson – PhD candidate

Chapter 6: Unveiling the Complexities of Mild Stroke: An Interpretative Phenomenological Analysis of the Mild Stroke Experience

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This chapter explores the underlying essence of the transitional experience for people with mild stroke, during the first 6 months after acute-hospital discharge. It follows the lives of five individuals, two who received MiStrEnGTH and three who received 'standard care', solidifying the commonalities and differences in their experiences and why these might occur. Participants were interviewed three times during the 6 months at 1-, 3- and 6- months post-discharge. This chapter represents the first of two results chapters that explore these participants' experiences, with this chapter focusing on the core of the general mild stroke transitional experience, and a latter chapter exploring their healthcare experiences. Two themes were identified to represent the essence of this phenomenon: 'Understandings and representation of stroke' which has two subthemes ('Society defines the stroke experience' and 'The past determines the present'); and 'Underlying relationship dynamics revealed'. These themes provide explanation for the experiences portrayed by the participants and are linked to the wider literature in order for readers to interpret them and transfer them to differing contexts.

The PhD candidate was primarily responsible for the design of this study, data collection and analyses, and writing of the article. Professor Louise Gustafsson contributed substantially to the article, assisting with data analyses, ensuring that all codes and themes were reflective of the raw data, and providing critical appraisal to writing. Associate Professor Petrea Cornwell participated in iterative discussions with the PhD Candidate and Professor Louise Gustafsson and provided critical appraising to writing.

Contributor	**Statement of contribution**
Tenelle Hodson (candidate)	Conceptualisation of research design and question (70%) Data collection (100%) Data Analysis (70%) Writing and editing of manuscript (70%)
Louise Gustafsson	Conceptualisation of research design and question (15%) Data collection (0%)

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	Data analysis (20%) Writing and editing of manuscript (15%)
Petrea Cornwell	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (10%) Writing and editing of manuscript (15%)

Miss Tenelle Hodson – PhD candidate

6.1 Abstract

Introduction: Limited research has been conducted from a longitudinal and qualitative perspective on the experience of life after mild stroke. This limits the knowledge held in this area, especially as to why people's experiences may differ. This study aimed to answer the question: How do people with mild stroke understand their experiences in the first 6 months after hospital discharge?

Methods: Interpretative phenomenological analysis, involving five participants with mild stroke of Anglo-Australian heritage, interviewed at 1-, 3- and 6- months post hospital discharge.

Results: Two themes emerged about the transitional journeys post mild stroke: (1) *Understandings and representation of stroke* and (3) *Underlying relationship dynamics revealed.* The first theme had two subthemes: (1) *Society defines the stroke experience* and (2) *The past determines the present.* The first of these reflected the impact that societal perceptions of 'stroke' had on participants' views of their mild stroke, including feelings of being 'lucky' even when experiencing hidden difficulties that were viewed as liveable repercussions. The second explores how previous health conditions acted as a mediator for participants' experiences of the mild stroke and how personality traits assisted adaption to post mild stroke changes. The final theme highlights how participants' relationships were either strengthened or weakened after the mild stroke, dependent on previous relationship dynamics.

Conclusion: Current societal perceptions of stroke are centred on 'observable' symptoms; however, more subtle symptoms common in the mild stroke population remain widely unknown by the general public impacting post-mild stroke experiences. Previous health conditions and personal qualities have an impact on how people react to their mild stroke and help to explain the individualist nature of mild stroke outcomes. Relationship dynamics prior to mild stroke can impact on post mild stroke family functioning and should be screened for and supported by health professionals. All of these factors emphasise the need for a patient-centred focus and multidisciplinary approach when determining appropriate intervention.

6.2 Introduction

Historically, erroneous assumptions have been made regarding 'mild stroke', with it being considered a 'benign' version of stroke (Yeo, Paliwal & Sharman, 2014). More recently, however, the topic of 'mild stroke' has gained research interest due to the identification of ongoing repercussions that follow such an event. Whilst there is yet to be an agreed upon definition of mild stroke (Spokoyny et al., 2015; Tellier & Rochette, 2009), it is often defined using the National Institute of Health Stroke Scale (NIHSS) using a score of ≤5 (Chang et al., 2017; Spokoyny et al., 2015). There is however debate amongst authors about this cut-off and others use alternative assessment tools (Tellier & Rochette, 2009). Whilst some people with mild stroke will experience limited difficulties following the event, others will present with impairments in various functional domains even with a NIHSS score of 0 (Chang et al., 2017). This re-enforces that 'mild' stroke is a condition with many and varied presentations (Chang et al., 2017; Hu, Heyn, Schwartz, & Roberts, 2017).

The myriad of issues experienced by people with mild stroke include: cognitive difficulties (e.g. memory issues), sensory difficulties (e.g. attentional neglect), physical risks and difficulties (e.g. limb weakness), and emotional disturbance (depression) (Finch et al., 2017; Hanney, 2012; Hu et al., 2017). Such limitations lead to difficulties performing activities of daily living and complex activities (Hanney, 2012; Hu et al., 2017). Further, these difficulties have been documented as present for at least 6 months post stroke (Chang et al., 2017). Quantitative studies in the mild stroke field have demonstrated factors that contribute to how each person's mild stroke may be experienced. Such factors include: age at stroke onset (Chang et al., 2017; Wise, Harris, Olver, Davis & Disler, 2018), functional ability during acute hospital stay (Chang et al., 2017), provision of thrombolysis, baseline functional status, activity level (Spokoyny et al., 2015), number of comorbidities, loss of consciousness, social integration ability level (Wise et al., 2018), and emotional support (Villain, Sibon, Renou, Poli, & Swendsen, 2017). Whilst these factors provide insight into the possible reasons for differing outcomes in the mild stroke population, qualitative investigations may provide further insight into the different experiences of people with mild stroke.

Qualitative explorations confined to the mild stroke experience are quite limited. For instance, a recent literature review exploring the qualitative understanding of the experiences of people with transient ischemic attacks (TIA) and mild stroke was only able to identify twelve articles that explored this phenomenon (Crowfoot, Van der Riet, & Maguire, 2018). This review emphasised that the social and personal lives of people in this population are impacted by the repercussions of the health event, but was unable to draw mild stroke specific conclusions as only

six articles focussed on people with mild stroke (Crowfoot et al., 2018). These six articles also had methodological limitations, with four being cross-sectional studies which limit the longitudinal understanding of the experience (Carlsson et al., 2009; Hillsdon et al., 2013; Taule & Råheim, 2014; Tellier et al., 2011), while four have a narrow focus of the mild stroke experience, including: return to work (Gustafsson & Turpin, 2012) experiences of a particular intervention (Hillsdon et al., 2013), experiences of spouses (Tellier et al., 2011), and exclusively male experiences (Green & King, 2009) reducing transferability. Conclusions from the literature review posited that there was a need for further qualitative research in order to understand the complex processes that underpin experiences for this population (Crowfoot et al., 2018). In addition to the twelve studies included in the literature review, a further two cross-sectional qualitative studies from Ireland (Hanney, 2012) and Denmark (Lou et al., 2017) have investigated the experiences of people with mild stroke, emphasising the stigma that younger people with mild stroke perceive and that the stroke event should be understood within the person's context (Lou et al., 2017).

It is clear that people with mild stroke have varying experiences after acute hospital discharge, but the literature that explores this phenomenon is quite finite. Further input is therefore required from both a longitudinal and qualitative perspective. For this reason, the current research project aims to answer the question: How do people with mild stroke understand their experiences in the first 6 months after hospital discharge?

6.3 Methods

6.3.1 Design

This qualitative study was completed alongside a randomised controlled trial (RCT) that examined the impact of a novel allied-health led, telehealth, stroke-specific self-management program (MiStrEnGTH – Mild Stroke Enhancing and Guiding Transition Home), in comparison to standard care. The RCT provided a unique opportunity to access participants with mild stroke and explore their experiences, consequently leading to the completion of this research. The current study is part of a program of qualitative research undertaken to understand the experience of mild stroke. The program follows a tiered approach of interpretative phenomenological analysis (IPA) outlined by Smith and colleagues (2009). This tiered approach starts with an in-depth exploration of one case, for this research program this included a person with mild stroke and their partner which was completed previously, followed by a larger study involving more individuals (Smith et al., 2009). Consequently, this study represents the second in this program of research. The IPA approach was chosen as it enables deep investigation of a specific experience (Finlay & Ballinger, 2006; Smith et al., 2009). Ethical approval for this study was obtained from the local ethics committees of the

hospital and health service in which this study took place, and relevant universities (approval numbers: HREC/15/QPCH/18; 2016000021; GU: 2015/884).

6.3.2 Research Characteristics and Reflexivity

The authors' ontological and epistemological beliefs aligned strongly with an IPA approach and the aim of understanding the lived experience of participants with mild stroke over time. The authors' adopted a relativist ontology, believing that reality is formed by people's perceptions and interactions and is expressed through language (Finlay & Ballinger, 2006). The authors' epistemological positioning aligned with an interpretivist stance, identifying that it is impossible for researchers to remain objective due to the fact their identity and standpoint shape the research process and findings (Finlay & Ballinger, 2006). Consequently, the following reflexive excerpt from the lead author must be taken into consideration when interpreting findings.

The first author acknowledges that she is in a position of privilege, being of middle income socioeconomic status and living in Australia. This may have influenced the questions she asked, the way she interacted with participants and her interpretation of interview transcripts. She is an early-career occupational therapist by background and therefore this may also have influenced how data was coded. The first author also acknowledges that she has not experienced a stroke herself, nor has anyone close to her and therefore her understanding of this phenomenon is purely from an academic and clinical perspective. Finally, the researcher was not involved in the participants' treatment nor employed in the facility in which their treatment took place, consequently reducing her familiarity with the context but allowing for a more objective analysis.

6.3.3 Participants

The participants for this study were consecutively recruited from the RCT, over the final 7 months of participant recruitment (November 2016-June 2017). All participants who met inclusion criteria for and were admitted to the RCT were eligible for inclusion in the current study. To be included in the RCT, participants had to: have an acute mild stroke diagnosis, be aged 18 years and over, be admitted to one of the hospital health service facilities included in the RCT, receive acute stroke management only, have a discharge destination of a home or community environment, and have adequate language and cognition to provide consent and complete outcome measures. People with a communication impairment were not excluded and a mild stroke diagnosis in the study was classified by a modified Rankin Scale (mRS) score of 0-2 determined by the acute management team.

IPA acknowledges the complexity of understanding human phenomena, and therefore advocates for studies to focus on a small number of cases (Smith et al., 2009). IPA researchers aim

to include three to six participants in their studies (Smith et al., 2009). This number enables the development of meaningful points of similarity and difference between participants, whilst also ensuring that the researcher is not overwhelmed by the amount of data generated (Smith et al., 2009). Consequently, this study aimed to recruit six participants in total, including three from each service stream into this study.

6.3.4 Procedures

During participants' acute hospital admissions, the RCT's project officer identified potential participants and obtained written consent to be approached to participate in qualitative interviews. Following provision of written consent, the lead qualitative researcher (TH) contacted potential participants and organised interviews. Whilst the aim was to recruit six participants, due to recruitment occurring at the later stages of RCT recruitment and project staffing issues, the number of potential participants was reduced. Consequently, fourteen people were identified as potential participants; however, nine were not able to participate as a result of: a change in diagnosis, palliation, declining participation, or an inability to contact. As a result, only five participants were able to be recruited. However, this number was observed to be appropriate to comply with IPA requirements for sample size as outlined above. For confidentiality purposes, all participants have been given a pseudonym. Participants were interviewed at approximately 1-, 3- and 6- months post hospital discharge. Interviews were conducted over the first 6 months post hospital discharge as this has been identified as the 'critical' transition period following stroke (Hall et al., 2012). All semi-structured interviews were completed in the participants' homes and lasted between 17- and 94-minutes. Efforts were made to ensure that participants were interviewed without the presence of family members, however, in some instances this could not be achieved. Interviews were audio-recorded and transcribed verbatim for later analysis.

An interview guide was utilised during all semi-structured interviews. Two open-ended questions led this interview: 'Tell me about your experience of returning home after having a stroke' and 'How has your experiences been with health services?'. This study utilised data obtained from the first of these questions, with a latter study addressing the second question. Additionally, probes in the following areas were used as needed and were identified from a thorough investigation of the literature: engagement in meaningful activity, community participation, quality of life, mood, driving, personal relationships, and lifestyle changes.

Data Analyses

An interpretative phenomenological analysis (IPA) approach (Smith et al., 2009) was used to analyse data. In order to complete this type of analysis, TH read through transcripts multiple times

to familiarise herself with the data (Finlay, 2011). Further, to ensure familiarisation was thorough, TH also listened to all audio-recordings whilst reading transcripts. Line-by-line coding was then completed, where initial interpretative comments were noted by TH (Finlay & Ballinger, 2006; Smith et al., 2009). These comments were then compiled and compared to identify emergent themes (Finlay, 2011; Smith et al., 2009). A second researcher (LG) concurrently read through data. Following this, both researchers engaged in an iterative discussion about the emergent themes until a final list of super-ordinate themes was developed (Finlay, 2011; Smith et al., 2009). Following the coding of all data and as a final check that these themes reflected the data, TH selected three interviews at random (one at each time point) and completed coding using these themes.

6.3.5 Rigour

To ensure rigour was upheld during the conduct of this study, a number of strategies have been taken. Firstly, to ensure the research is trustworthy, clear descriptions have been provided that are in line with what participants reported and which provide illumination on the phenomenon in question. Transferability has been achieved through the provision of information about the participants' intervention contexts and their demographic details, which enables readers to determine whether the context in which this study occurred, and the participants within it, are applicable to their research population or patients. Credibility in this study has been achieved by: having interview questions and probes discussed and decided upon by three researchers; the interviewer summarising interpretations of what participants said at the end of each interview so that participants could suggest any changes; having consistent transcription methods; providing a detailed description of the steps taken during data analysis; and the provision of participant quotes to substantiate findings. Dependability was demonstrated in the current study through having the same researcher complete interviews at each time point. Furthermore, the same interview questions were asked at each interview time point, time was taken between each coding round and a second researcher completed coding until intercoder agreement was achieved.

6.3.6 Health Services Context

Participants in this study either received 'standard care' provided by the hospital and health service at which they presented with the mild stroke, or MiStrEnGTH in addition to 'standard care'. 'Standard care' for these participants included any of the following: stroke education, referral to a general practitioner (GP) and a discharge report, referral to an outpatient clinic follow-up appointment at 1- to 3- months post discharge, provision of information regarding peer support groups, or a referral to and information regarding local community-based programs and services. The MiStrEnGTH program involved an experienced allied health professional (AHP) conducting

telephone calls during the first 6 months post-hospital discharge in order to assist people with mild stroke to: manage their symptoms, address physical and psychosocial difficulties, meet rehabilitation needs, and improve their lifestyle. In total, five telephone consultations were performed at approximately: 1-week post-discharge, 4- and 8- weeks post-discharge, and two within the 3- to 6- months post-discharge at the discretion of the individual. Within each telephone consultation, the AHP would guide the person through self-management of their mild stroke by having them: reflect on areas of change since the stroke, identify current supports and unmet needs, set goals, and develop plans to address these goals. Further, the AHP provided education on where the participant may be able to obtain more information.

6.4 Results

Participants within this study had varying backgrounds and differing life circumstances, see Table 6.1. All had an ischaemic stroke, were independent in activities of daily living and did not require walking aids to mobilise post mild stroke, except for one participant due to a previous condition. The key themes of this study reflect the underlying ‘essence’ that contributes to making each person with mild stroke’s journey different and were present throughout the 6 months of interviews. Two themes were identified: ‘Understandings and representation of stroke’ and ‘Underlying relationship dynamics revealed’.

Table 6.1: Demographic Table

Participant	Shane	Kerry	Neil	David	Tom
Gender	Male	Female	Male	Male	Male
Age	40	48	65	45	64
Living Circumstances	Home with Family	Home with Family	Lives Alone	Home with Family	Home with Spouse
Employment (Pre-Stroke)	Full-Time	Unemployed	Retired	Unemployed	Full-Time
Hospital Length Of Stay (Days)	9	5	6	2	5
Intervention Received	Standard Care	Standard Care	Standard Care	MiStrEnGTH	MiStrEnGTH
Community Services	No	No	Yes	No	Yes
Stroke Location	L) Thalamic	R) Capsular	Posterior L) Frontal	L) Middle Cerebral Artery	L) Medial Pontine
mRS	2				2
Cognitive Score	MOCA 27/30		MOCA 29/30		MOCA 24/30
Functional Status	Nil Aids	Mobility Aids	Nil Aids	Nil Aids	Nil Aids

6.4.1 Understandings and representation of stroke

This theme reflects how mild stroke was understood and interpreted by participants. It appeared that their experiences were influenced by both societal understandings of stroke and inherently through their own life experiences. Consequently, two sub-themes have been identified: 'Society defines the stroke experience' and 'The past determines the present', that reflect each of these ideas.

6.4.1.1 Society defines the stroke experience

Participants alluded to a societal view of 'stroke' as an observable condition that occurred in older adults. For some, this perception contributed to the 'shock' of experiencing such an event at a younger age, which David demonstrated when he said '*…But still, yeah, it was a surprise. I'm only 45-46'* (1-month interview). This view, and the expectation of severe effects from the stroke, appeared to impact the way they experienced their transition following their mild stroke event. For instance, whilst many of the participants were left with hidden difficulties, they viewed themselves as 'lucky' as their issues were not as obvious as those experienced by their moderate to severe counterparts, observed in the following quote from David:

> *'…as you can see, I've got stairs and all that sort of stuff, so there's things that most people might have issues with after having a stroke. I just – I haven't had any mobility issues. I haven't had any cognitive issues'* (1-month interview)

This idea of being 'lucky' represented a unique phenomenon of what could be perceived as 'liveable repercussions'. Liveable repercussions appeared when participants identified changes in their lives since the stroke event, that they were prepared to live with or were not actively seeking further help for. This sense of inaction towards changes in their lives seemed to occur as a result of not deeming them 'significant' enough to raise concern. Neil alluded to this when he discussed how he had noticed speech changes when he was excited, but did not feel like he socialised enough for them to create an issue, *'…I still have trouble speaking sometimes, but…I don't really speak a lot.'* (3-month interview).

In conclusion, the way that people had internalised societal views surrounding illness and 'stroke' influenced the way they experienced the condition.

6.4.1.2 The past determines the present

It was clear from participants' discussions that their past experiences, especially with health conditions, shaped the way they viewed their mild stroke and how they adapted to it. Due to this, previous health conditions were a source of comparison and determined how people perceived the severity of repercussions experienced. This was reflected in a number of ways, and either assisted with adaptation or increased the difficulty of the adaptation process. For instance, Kerry, who had

an ongoing chronic health condition that impacted her daily life felt that the mild stroke was like nothing that she had experienced and had been the trigger to a series of changes in her life. The following passage from her 6-month interview demonstrates the changes she had experienced in her emotions following the stroke.

> *'…as far as emotions and stuff like that, which I never used to show a lot…I always used to say, like, leaking* [crying] *is weak. Uh, didn't like it and now – now that's all I do, it [cusses] me... Anything just makes me leak, and I really can't stand it, because that's not who I am.'*

Alternatively, David who also had been living with a chronic condition felt that he had already experienced a number of changes in his life and took it in his stride; the mild stroke paled in comparison to his previous condition.

> '*When I had the brain surgery I stopped working and I haven't gone back to work since. So we've had a huge amount of changes since then. Um, so I'm fairly rambunctious when it comes to dealing with change…'* (1-month interview)

Previous life experiences, including health conditions, also appeared to engender personal qualities or coping strategies that assisted with reacting to changes following the mild stroke and contributed to the adaptation process. Attributes that participants possessed included: hope, flexibility, perseverance and defiance. Hope was often portrayed through participants' beliefs that things would get better or that they would be able to re-engage in activities as they previously had before the stroke. On the other hand, when participants had to alter the way they completed activities they demonstrated flexibility and therefore an ability to continue their participation in meaningful activities. An example of how perseverance and defiance aided in adjusting to difficulties was discussed by Shane. In the following quote, Shane voices his difficulties with completing paperwork for his son's school excursion and the fact that, whilst he was frustrated he continued to work through the documentation in order to meet his son's needs.

> *'But I can still do it just takes me a bit more time to – to work on it, you know, don't give up on it and I work my way through it.'* (6-month interview)

It is therefore evident that the person's past and personal qualities contribute to their reaction to the mild stroke event.

6.4.2 Underlying relationship dynamics revealed

The mild stroke appeared to unmask underlying dynamics within families. Whilst all participants reported appreciation for their family members, there seemed to be a continuum in regards to the relationships they had with family members. For those that had solid foundations, the mild stroke

clearly demonstrated the strength of the relationship and how families would work together in order to adapt as one. For these participants, a sense of positivity was expressed when discussing their relationships with families or spouses, and it appeared that they saw such people as being helpful in their transitional journey. This was not always explicitly stated but could be identified in the fondness that participants portrayed in relation to their loved ones, especially during times when they were receiving assistance from them. This was observed in an interview with Tom when he spoke of the period of time when his wife completed all the driving due to medical restrictions on his own license.

T: *She was doing all the driving.*

I: *-yep, can you tell me a bit about what that was like for you?*

T: *Oh I wasn't in control, was I [laughs]..nah it was pretty good. She's a good driver. She's, you know, got her way into the hospital and all that sort of thing, cause she hates driving in traffic. It was out of her comfort zone, which, which was good for her as well.* (1-month interview)

For those with more complex relationships within their households, the mild stroke unravelled relationships as changes to their everyday life occurred. Changes to participants' lives such as loss of income due to an inability to work or altered behaviours as a result of sensory processing issues increased the stress that was present within households. As this stress increased, cracks started to appear within relationships and, for some this led to the end of relationships. A poignant reflection of this came from Shane *'…the other person under this roof wants to trade me in and get rid of me because of how much I've apparently changed since me stroke.'* (6-month interview).

Overall, it appeared that the mild stroke event had an impact on relationships during the transitional continuum.

6.5 Discussion

This study found that the transitional experience for people with mild stroke following hospital discharge is influenced by societal perceptions of stroke, and pre-morbid life conditions and experiences. Some of the factors within these elements that may contribute to one path being experienced over another were foregrounded. This discussion will aim to explore these factors in greater detail and determine the implications of these findings.

Firstly, the common societal view of 'stroke' appeared to manipulate the experience of participants in this study. Much of the public knowledge regarding stroke appears to be centred on the acute stage, which could be a result of the F.A.S.T (Face.Arm.Speech.Time) campaigns in places such as Australia (Bray, Mosley, Bailey, Barger, & Bladin, 2011), the United Kingdom

(Dombrowski et al., 2013), Ireland (Hickey, Mellon, Williams, Shelley, & Conroy, 2018) and the United States (Wall, Beagan, O'Neill, Foell & Boddie-Willis, 2008). Whilst these campaigns have contributed to public awareness of how to identify a stroke (Bray et al., 2011; Dombrowski et al., 2013; Hickey et al., 2018; Wall et al., 2008), they are unable to provide knowledge to the public about life after stroke and how this might present. The F.A.S.T campaign also focuses on observable signs of stroke (Dombrowski et al., 2013), which may exacerbate public expectations of how 'stroke' should appear. This has been supported by a previous study where people with stroke reported that they did not think they would receive attention for their milder symptoms (Yoon & Byles, 2002). Stone (2005) further discussed the implications that a lack of understanding around the different representations of stroke had in her study of women who had experienced haemorrhagic strokes under the age of 50. Within the study, it was evident that when societal perception solidifies the need for 'disability' to be observable it leads people with more subtle symptoms to adopt this idea (Stone, 2005). This can then result in a denial of any ongoing difficulties as they may not be viewed as serious enough to warrant attention or can create a feeling of 'attention seeking' if people do inform others of their discreet difficulties (Stone, 2005). These findings were supported in the current study, where participants thought they were lucky to have had a 'mild' stroke and did not think that their repercussions warranted as much attention as others'.

In addition to societal perceptions, prior life experiences, especially those related to health conditions, altered the person's perception of the stroke event. For some participants in the current study, prior conditions had resulted in adaptations and changes in their life, whereby the resulting mild stroke had less of an impact. This has previously been discussed in the ageing literature, where it has been demonstrated that accumulated life experiences are often seen as an explanation as to why older adults may fare better in the face of health problems (Rybarczyk, Emery, Guequierre, Shamaskin & Behel, 2012). This can be framed within the 'inoculation' hypothesis, which suggests that previous negative life events can create an immunity from strong emotional reactions when faced with similar situations (Eyseneck, 1983; Rybarczyk et al., 2012). In contrast, there were participants in the current study who expressed the major impact mild stroke had had on their lives despite previous adaptations and changes from pre-existing chronic conditions or traumatic events. This could be reflective of the fact that multi-morbidity can compound the effect of living with individual chronic conditions by magnifying symptom burden (Wister et al., 2016). The cumulative effect of multi-morbidity disease-related losses may also bring illness to the foreground of people's minds, resulting in it occupying greater space in their life (Paterson, 2001). This juxtaposition of

outcomes created by prior experiences instils the individualistic nature of the mild stroke experience.

Personal attributes also appeared to assist participants in this study to adjust and adapt to life after mild stroke. The results identified that perseverance, hope, flexibility and defiance were particular enablers to adjustment. The presence of personal qualities that assist in the adaptation to health events has been supported in the literature outside the stroke-specific field. For instance, Rybarczyk and colleagues (2012) reported that optimism, hope, resilience and a sense of humour all assist in the adaptation process. Further, they discussed the role of positive reframing in the adaptation process, whereby the person is able to re-label illness factors and changes in a more manageable manner (Rybarczyk et al., 2012). Alternatively, by viewing this phenomenon through the works of Kleinman (1988) it may be speculated that participants were demonstrating a 'quiet heroism' where they may have been utilising grace, spirit and humour on a daily basis to live to the best of their ability in the presence of mild stroke. Either way, the current study emphasises the role that personal attributes may have on the mild stroke experience.

The final theme in the current study revealed how relationship dynamics influenced the transitional journey for people with mild stroke. It appeared that participants who had strong relationships with family members prior to the stroke event were able to experience growth and consolidation of these. On the other hand, others with more complex family situations appeared to experience further cracks in their relationships after the stroke. Whilst this appeared to be the narrative in the current study, it must be acknowledged that this is a simplistic view on relationships following mild stroke, and that in fact a number of journeys may be taken in a relationship following a mild stroke. It has been previously stated that whilst the presence of a social support network can be protective, it is the quality of the support that is received that is truly important (Greenberg, 2007). As a result, stressful relationships may be correlated with numerous health implications (Greenberg, 2007). This supports the current findings, as whilst all participants had some form of social support, those that had more complex relationships prior to the stroke experienced s social context that created more stress for the person with stroke. Alternatively, other researchers have posited that the fit between an individual's capacities, competencies and attributes, their social support and the losses experienced from an illness event contributes to their ability to be resilient (Greve & Staudinger, 2006; Leipold & Greve, 2009). This makes interpreting the current results more complex. Whilst it may be that some participants had weaker social relationships, it may also have been that they experienced more loss or had reduced personal capacity to respond to the stroke event which impacted their social relationships. Either way, it is known that better

functioning does result from increased social support (Sells et al., 2009) and more focus should be given to supporting family members of people with mild stroke to understand changes that occur. More research into the underlying cause of relationship breakdown after mild stroke is required, with particular attention paid to gender roles and expectations, experiences of same-sex couples, as well as communication between spouses.

6.5.1 Limitations

The current study was restricted to the experiences of five individuals with mild stroke within one location in Australia, therefore limiting generalisability. To compensate for this, extensive detail has been provided about the context in which the study occurred in order to enhance transferability. Furthermore, participants were partaking in a RCT during the interviews period which may have altered their specific experiences post mild stroke.

6.6 Conclusions

This study explored the essence of the transitional experience for people with mild stroke from a longitudinal perspective. Findings demonstrate that the mild stroke experience is heavily influenced by societal views of 'stroke'. Further, previous life experiences and personal attributes appeared to determine how the person responded to the stroke event, emphasising that services provided to people with mild stroke need to consider the individual, their characteristics and their past when identifying care needs. Finally, the role that a mild stroke event can have on revealing underlying relationship dynamics was emphasised. Overall, it is evident that a mild stroke event will have a different impact on each individual, however the influences identified in this study can improve the understanding of possible factors to consider when treating individuals with mild stroke.

6.7 Chapter Summary

This chapter has explored the longitudinal transitional experience of five people with mild stroke, who either received 'standard care' or MiStrEnGTH. The chapter has revealed some of the underlying reasons as to why people with mild stroke have differing transitional experiences. The two themes 'Understandings and representation of stroke' and 'Underlying relationship dynamics revealed' were identified in relation to this. As mentioned at the start of this chapter, this chapter represents one half of these particular participants' experiences, with the following chapter exploring the healthcare experiences of these participants. Consequently, this chapter has served to address the first overarching research question of this thesis and the next chapter will address the second research question.

Miss Tenelle Hodson – PhD candidate

Chapter 7: The Healthcare Experiences of People with Mild Stroke: An Interpretative Phenomenological Analysis

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). The Health-Care Experiences of People with Mild Stroke: An Interpretative Phenomenological Analysis. *Submitted to: Disability and Rehabilitation*

In this chapter the essence of the healthcare experiences of five individuals with mild stroke, under two models of care is identified. The five individuals were interviewed at 1-, 3- and 6- months post acute-hospital discharge. Three themes were identified as portraying the essence of these individuals experiences: 'The difficult diagnosis', 'Standard care: good but not good enough', and 'A journey better not done alone'. The discussion section of this chapter links the findings to the current evidence base and puts forth recommendations for future research and clinical practice.

The PhD candidate was primarily responsible for the design of this study, data collection and analyses, and writing of the article. Professor Louise Gustafsson contributed substantially to the article, assisting with data analyses, ensuring that all codes and themes were reflective of the raw data, and providing critical appraisal to writing. Associate Professor Petrea Cornwell participated in iterative discussions with the PhD candidate and Professor Louise Gustafsson and provided critical appraising to writing.

Contributor	**Statement of contribution**
Tenelle Hodson (candidate)	Conceptualisation of research design and question (70%) Data collection (100%) Data Analysis (70%) Writing and editing of manuscript (70%)
Louise Gustafsson	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (20%) Writing and editing of manuscript (20%)
Petrea Cornwell	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (10%) Writing and editing of manuscript (10%)

Miss Tenelle Hodson – PhD candidate

7.1 Abstract

Purpose: A shortage in mild stroke services has resulted in a lack of understanding of how this population experiences health services, restricting advancement in the area. With recent acknowledgement of the difficulties that this population faces, it is imperative that their views are sought on the services required to meet their needs. This study was guided by the question: 'How do people with mild stroke perceive their experience of stroke-related healthcare services?'

Materials and Methods: Qualitative investigation using an interpretative phenomenological analysis. Five participants were interviewed at 1-, 3-, and 6- months post discharge. Satisfaction with health services was measured using a 10-cm visual analogue scale and used for data triangulation.

Results: Three themes were identified that reflected the 'essence' of healthcare service experiences: 1) 'The difficult diagnosis', 2) 'Standard care: good but not good enough,' and 3) 'A journey better not done alone'.

Conclusions: Issues were identified during the diagnostic period of participants' journeys which require further attention. Following hospital discharge issues relating to service coordination, information provision and secondary prevention were identified. Finally, a formal support person was viewed as beneficial in increasing participants' feelings of comfort and support.

7.2 Introduction

Research documenting the outcomes of mild stroke has gained momentum in recent years. It is the presence of ongoing implications after mild stroke that has sparked this interest. Whilst a mild stroke results in less 'observable' symptoms than its more severe counterparts, it has been indicated that contextual factors in the person's life contribute to the severity of its implications (White, Attia, Sturm, Carter, & Magin, 2014; Wolf et al., 2009). For instance, people under the age of 65 make up a large proportion of the mild stroke population and are often working full-time and raising a family at the time of the stroke (Lannin et al., 2017; Wolf et al., 2009). This can result in productivity and economic implications, especially when services to assist in community reintegration and return to work are not provided (Burns et al., 2018; Wolf et al., 2009). Currently there is a dearth of mild stroke specific services, with ongoing implications for health services and society in general (Wolf et al., 2009) and potential increased likelihood of subsequent strokes for the person (White et al., 2014). As a result of limited mild stroke specific services there is also minimal understanding of this population's experiences of health services (Burns et al., 2018; Lannin et al., 2017) restricting advancement in the field.

People with mild stroke contribute to approximately half of the overall stroke population (Burns et al., 2018; Wolf et al., 2009). However, the inability to detect ongoing difficulties in this population during acute hospital stay is one of the key factors that results in limited access to ongoing services (Burns et al., 2018). Current acute stroke assessment tools target people with moderate to severe stroke resulting in people with mild stroke presenting quite 'well' on all measures (Burns et al., 2018; Terrill et al., 2018; Wolf et al., 2009). This results in healthcare services being directed towards the more severe consequences of stroke, such as basic activities of daily living (Burns et al., 2018; Wolf et al., 2009) rather than the more subtle difficulties experienced by the mild stroke population. Consequently, factors associated with community integration relevant for people with mild stroke remain unaddressed (Wolf et al., 2009) and enhancement of services is required to support their transition back to community living (White et al., 2014).

One example of an initiative to bridge this gap and increase follow-up of all people with stroke in Australia is StrokeConnect. StrokeConnect is a program that aims to connect people affected by stroke with information, services, support and recovery (Stroke Foundation, 2018a). Two elements of this program are highlighted in the Stroke Foundation's Clinical Guidelines for Stroke Management 2017 as initiatives that support transition and community participation, EnableMe and StrokeConnect Follow Up (Stroke Foundation, 2018b). EnableMe is a self-directed

web-based resource that provides personalised information and tools to set and address goals and identify relevant supports (Stroke Foundation, 2018b). StrokeConnect Follow Up consists of a health professional phoning people with stroke at 6 weeks post hospital discharge to provide information and advice on stroke prevention, treatment and recovery and to determine if a second phone call is needed (Stroke Foundation, 2018b). This service has the potential to provide additional support to people at one relatively early time point in the transition continuum. However, there is currently limited published research available about these initiatives including people's experiences of them, their uptake, or efficacy. Additional questions that remain include how, and if, the services provide support across the critical transition period of 6 months for people with stroke and if the services target the issues specific to mild stroke (Hall et al., 2012).

Internationally, research into mild stroke services is emerging but there are still gaps to explore. A scoping review of mild stroke specific services provided after hospital discharge and that focus on person-centred secondary prevention and adaptation to new-found changes, identified that only twelve programs met this criteria internationally (Hodson et al., 2017). The programs that were included consisted of: telehealth programs, exercise programs, comprehensive cardiac rehabilitation, one-off visits with care plan development, and community group programs (Hodson et al., 2017). The majority of these focussed on secondary prevention or were aimed at person or impairment level (Hodson et al., 2017). Consequently, a large proportion of the studies did not target emotional well-being, performance of complex activities, or contextual factors (Hodson et al., 2017). Furthermore, the majority of these studies were relatively short-term and did not have adequate follow-up to identify ongoing impact (Hodson et al., 2017). It is therefore clear that further research into mild stroke specific services is necessary.

To meet the needs of the mild stroke population, their perspectives of current services need to be gained and they should be engaged during the development of future services (Turner et al., 2018). Due to increased access to health information through internet and social media sources, consumers are becoming increasingly interested in matters of their own health and illness, seeking professional help with pre-conceived expectations, ideas, questions and needs (Benetoli, Chen. & Aslani, 2018; Faltermaier, 1997). In order for healthcare services to meet these expectations and ensure patients remain compliant with interventions, they can no longer be guided only by expert opinion (Faltermaier, 1997) but must value consumer contribution and information exchange (Benetoli et al., 2018). Consequently, it is pertinent that mild stroke services are explored from a qualitative perspective. The research question for this study was: 'How do people with mild stroke perceive their experience of stroke-related healthcare services?'

7.3 Materials and Methods

This study was embedded within a randomised controlled trial (RCT) that aimed to determine the efficacy of a novel allied-health led, telehealth stroke specific self-management service (MiStrEnGTH – Mild Stroke Enhancing and Guiding Transition Home), in comparison to standard care. This allowed for a unique opportunity to gain individuals perceptions on both models of care through qualitative research. A program of qualitative research was therefore undertaken using an interpretative phenomenological approach outlined by Smith and colleagues (2009). This approach utilised a tiered structure of investigation starting with an in-depth exploration of one case followed by a larger study involving more individuals. Consequently, this study is the third in the program of research (Smith et al., 2009). The details of both models of care are outlined below. Ethical approval was obtained from the local ethics committees of the hospital and health service in which the study took place, and relevant universities (approval numbers: HREC/15/QPCH; 2016000021; GU: 2015/884).

7.3.1 Standard Care

Standard care was completed by the participants' acute stroke teams at their treating hospitals. It consisted of any of the following: stroke education, a general practitioner (GP) referral and discharge report, a follow-up appointment at an outpatient clinic, peer support group information provision, or a referral to or information provision on local community-based support programs and services.

7.3.2 MiStrEnGTH

In addition to standard care, MiStrEnGTH participants received a tailored program that involved five telephone calls in the initial 6 months following hospital discharge from an experienced allied-health professional (AHP). The first three appointments were scheduled at 1-, 4- and 8-weeks post discharge. The final two appointments were scheduled at intervals mutually agreed upon by the AHP and the participant. Each telephone session utilised motivational interviewing and shared decision making to guide: reflection on areas of change, areas of progress, and achievements made; identification of areas that had been impacted, current supports and unmet needs; goal planning, where participants learnt how to develop their own goals and action plans to achieve these; and an educational component where the therapist assisted participants to identify ways of obtaining information. Participants had the opportunity to contact the AHP between sessions if needed.

7.3.3 Participants

Participants were consecutively recruited from the RCT (See Table 7.1). The intention was to include three participants from each model of care; however, as a result of the qualitative

component being introduced at a later point in RCT recruitment, only two MiStrEnGTH participants were able to be included. All participants have been given a pseudonym to comply with confidentiality protocols.

The following inclusion criteria were utilised in the RCT: age of 18 years or older, diagnosis and admission for management of a mild stroke, acute mild stroke management only, discharge destination of home or community environment, and adequate language and cognition to provide informed consent and complete outcome measures and interviews.

7.3.4 Data Collection

When recruiting participants to the RCT during hospital admission the project officer gave them the opportunity to be approached for participation in the qualitative interviews. Participants who were willing to participate in interviews gave written, informed consent. The project officer then notified the lead qualitative researcher (TH) who contacted potential participants and organised interviews.

Participants were interviewed at approximately 1-, 3- and 6- months post hospital discharge within their homes. These interviews were guided by two open-ended questions: 'Tell me about your experience of returning home after having a stroke,' and 'How has your experience been with health services?'. The second question was the focus of analysis for this study. Interviews lasted between 17 and 94 minutes, were audio-recorded and transcribed verbatim. As part of RCT data collection, 10cm visual analogue scale (VAS) scores for satisfaction with health services were collected.

7.3.5 Analysis

An interpretative phenomenological analysis (IPA) approach was used for data analysis (Smith et al., 2009). This involved TH listening to and reading through transcripts multiple times to become immersed in the data (Finlay, 2011). TH then completed line-by-line coding, noting initial interpretations (Smith et al., 2009). Initial codes were condensed into emergent themes and presented to a second researcher (LG) who had concurrently read the data. The two researchers then engaged in an iterative discussion to decide on a final list of themes. TH then completed a final check of all interviews, to ensure that the final themes were truly reflective of participants' experiences. Reflexivity was undertaken throughout the study by engaging in member-checking and prolonged engagement in interviews (Finlay, 2011;Smith et al., 2009). To complete member checking TH gave a verbal summary of her understandings at the end of each interview and the start of subsequent interviews. As a measure of triangulation, the VAS scores of patient satisfaction with care were utilised to compare participant reports to self-rated quantitative data.

Table 7.1: Participant Demographic Information

Participant	Dave	Jodie	Colin	Paul	Graeme
Gender	Male	Female	Male	Male	Male
Age	40	48	65	45	64
Living Circumstances	Home with Family	Home with Family	Lives Alone	Home with Family	Home with Spouse
Employment (Pre-Stroke)	Full-Time	Unemployed	Retired	Unemployed	Full-Time
Hospital Length of Stay (Days)	9	5	6	2	5
Intervention Received	Standard Care	Standard Care	Standard Care	MiStrEnGTH	MiStrEnGTH
Community Services	No	No	Yes	No	Yes
Stroke Location	L) Thalamic	R) Capsular	Posterior L) Frontal	L) Middle Cerebral Artery	L) Medial Pontine
Functional Status	Nil Aids	Mobility Aids	Nil Aids	Nil Aids	Nil Aids

7.4 Results

All participants had an ischaemic stroke and were independent in activities of daily living, see table 7.1 for further participant demographic details. This study revealed the essence of participants' experiences with healthcare services after mild stroke. Three key themes were identified, each dominating at a different point along the transitional continuum. These themes were: (1) 'The difficult diagnosis', (2) 'Standard care: good but not good enough', and (3) 'A journey better not done alone'.

7.4.1 The difficult diagnosis

This theme represents the initial stages of participants' journeys and the issues they experienced during the diagnostic period. Most of the data related to this theme was observed in the 1-month interviews, with minor reiterations of these sentiments occurring in follow-up interviews. By observing these difficulties this theme demonstrates limitations in current acute stroke practices.

Due to the symptoms that presented during their mild stroke events, the majority of participants did not identify that they had experienced stroke. For instance, Dave spoke of re-occurring headaches and visiting his general practitioner (GP) in order to determine the underlying cause:

> *'I went to the doctor and, um, you know, having a few extra headaches that, you know, that weren't normal so…So, wanted the glitch checked just to make sure everything was all good on that side and that's how they found it.'* (1-month interview)

Jodie on the other hand, had experienced a previous stroke and was advised to check her strength when suspecting further incidents. When her mild stroke occurred, however, she was able to demonstrate strength, leaving her confused:

> *'I just didn't – I said, "I've still got my strength." Because we always check – they told us to always check my strength.*' (1-month interview)

Not only were some of the presenting symptoms of the mild stroke confusing, but Graeme also experienced odd symptoms prior to his stroke.

> *'…well I went to the doctor's and he told me that I had a lung infection…Well the hospital did, and then I went back to the doctor's and he said, I don't think, I think it was more than that. And then the next morning I had the stroke.'* (1-month interview)

It is clear from these findings that the participants were aware that something was not quite right at the time of their mild stroke, but they did not identify it as a stroke.

Not only did participants experience issues with linking their symptoms to stroke, but medical staff also struggled with the ambiguity of their symptoms. For instance, two participants reported presenting to smaller hospitals and were sent home on the same day, without a diagnosis.

> *'They sent me to [Location] Hospital, who sent me home.'* (Colin, 1-month interview)
>
> *'…cut a long story short, I went to the hospital four times, they discharged me each time, said nothing was wrong...'* (Paul, 1-month interview)

For these two participants, it was clear that investigations had not been thoroughly completed, with Paul in particular speaking of his frustration with inadequate assessment.

> *'…my condition was hard to diagnose…Um, but, I think they were more trying to save money by not giving me an MRI, um, than actually giving me what I needed.'* (1-month interview)

As a result, these participants and their families had to be persistent with seeking medical advice in order to obtain appropriate medical assessment and intervention. Alternatively, after presenting at his GP, Dave was sent for scans at a tertiary hospital, but was not made aware of symptoms potentially relating to stroke.

> *'I actually went into, drove myself into the [Hospital] to, um, have the scan done then left there, come home and I was just in the mid process of grabbing me bag and everything to drive [for work] that night, when the phone call from the [Hospital] to say, um, "no turn around and come back to hospital."…And that's, you know, been probably the biggest bamboozle of the whole thing…'* (1-month interview)

These diagnostic delays led to increased risks of subsequent strokes and hazardous situations.

Overall, it appeared that participants experienced issues during the diagnostic period. Difficulties in identifying participants' strokes appeared to stem from their more subtle symptoms and subsequent lack of investigation, particularly in smaller hospitals and general practices.

7.4.2 Standard care: good but not good enough

The theme of 'Standard care: good but not good enough' expands over the first 6 months post-hospital discharge, however the majority of data that supports it is derived from the initial two interview time-points, with confirmations expressed during the last interview. Therefore, this theme emphasises the health service experiences that occurred between 1- and 3- months after hospital discharge.

In the initial period after discharge, participants reported feelings of satisfaction with health services. Participants expressed this with statements like *'…treatment at the stroke unit was good'* (Paul, 1-month interview) and *'…everyone was just fantastic…'* (Graeme, 1-month

interview). Participants also reflected on allied health professionals and nurses that provided information or intervention during their hospital stay, both of which were appreciated. At 1-month post-discharge it was clear that participants still identified their acute-hospital experience as their main healthcare interaction at this time, resulting in overall perceptions of services being good. However, as time from acute-hospital discharge grew discrepancies in healthcare experiences began to appear.

Firstly, it became apparent that a lack of service co-ordination was experienced. It seemed that services were provided in a way that favoured health settings but were not always conducive to participants' lives. For Jodie, this was reflected in her receiving a notification of a follow-up appointment at the last minute:

> *'…I was in [another location] and then I got a, a message saying that it was for the next day but I was in [another location]…'* (3-month interview)

This lack of cohesion between the health setting and participants' lives led to missed appointments and confusion around what services had been received. Relationships with general practitioners (GPs) therefore appeared to be increasingly important as they were often the only health service that had been accessed on a somewhat regular basis. However, issues with cognition post-stroke also presented difficulties in accessing this form of care:

> *'…I would think about going yep, I've got to go see him [GP] and then forget about it, you know?'* (Dave, 3-month interview)

Participants reported that their GPs managed their stroke through secondary prevention medications; however other approaches such as exercise, diet and stress management received less attention.

A sense of restriction from health services rather than enablement was apparent in these early months. Participants indicated that they were told what they should not do, but not what they could do. For instance, they were told that they could not drive for a month, but not informed about how they would return to driving; or they were told to reduce exercise-activity, but not told when or how they could return to exercise. Colin elaborated on the negative impact a problem-focused approach had on him:

> *'…the way they – they talk about, you know, well you're a male. Males are predestined to have you know, small strokes. And I think they should be looking at more that, it was only a little stroke…'* (1-month interview)

Finally, there were areas of information provision where participants recalled receiving no information, including: accessing pathways of care, financial support, and intimacy. Overall,

it appears that whilst health services and professionals are partially meeting the needs of this population, gaps in services remain.

7.4.3 A journey better not done alone

'A journey better not done alone' emphasises the appreciation participants had towards a formal support person throughout their transitional experience. Consequently, data was present in all interview time-points. For people who received the MiStrEnGTH program, this formal support person was the allied health professional that phoned them. For standard care participants, this appreciation was directed towards the presence of researchers.

Participants' descriptions of their journeys revealed an incongruity between experiences. Whilst MiStrEnGTH participants did not explicitly describe the benefits of the program, it was clear that their journeys were more positive in comparison to standard care participants. For instance, they were able to identify that they had received contact from stroke-related services, such as *'…I've had a couple of calls from the stroke unit to see how everything is going…'* Paul (3-month interview). Furthermore, they expressed feelings of security in regards to their health needs, with Graeme stating *'Oh look, no, I, I think, you know, I am supported'* (3-month interview). Consequently, whilst MiStrEnGTH participants did not explicitly state what the program did for them, it was clear that they were satisfied with their continuity of care.

Standard care participants on the other hand expressed confusion over services that they had received since discharge. This was reflected in such statements as *'So no. Pissed off, really'* by Jodie at 1-month post-discharge when asked if she felt supported, and *'I have no idea who to ask'* when asked who she would turn to if she had stroke-related issues. Colin at 6 months reiterated this sentiment, stating *'Oh, not really. I've been to the doctor. That's about it'* in response to whether he had been contacted by health services over the previous 6 months. Additionally, Dave spoke of his lack of knowledge regarding how to obtain his heavy vehicle-license at 6 months post-discharge in order to return to work, and an overall lack of support:

> *'…So, you know, where am I in the – in the – in this whole picture?...I've got to sit back in limbo myself going, all right, scratch, scratch, scratch, scratch. What am I allowed to do, what can I do,…'*

At the same time, he also expressed the appreciation he had towards having someone to talk to, in the form of researchers:

> *'Yeah, so it's someone's, just making sure that, you know, you might as well say that the I's are dotted…You know, whether it's, um, doing the questionnaires or making, you*

know, on what's happening or, you know, anything like that, or down to just having a chat about things.' (1-month interview)

Overall, this theme supports the need for ongoing follow-up in the mild stroke population, to increase feelings of support and confidence in returning to community life.

7.4.4 10cm visual analogue scale scores for patient satisfaction with care

Overall, high levels of satisfaction with hospital services were observed in participants 10cm VAS scores. The highest scores occurred at hospital discharge to 1-month, with a slight decrease observed at 3- and 6- months. Interestingly this decline was most obvious for Dave and is consistent with their experiences summarised in 'A journey better not done alone'.

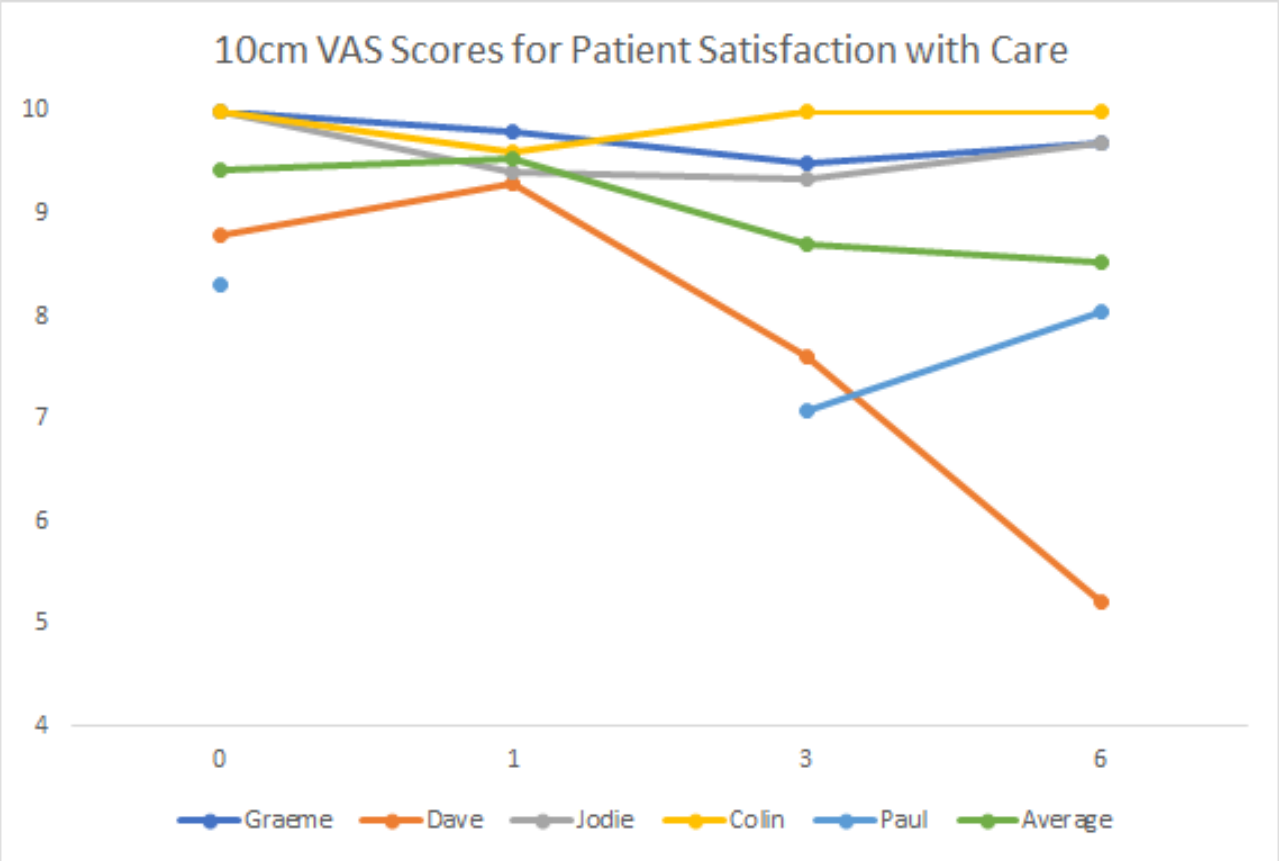

Figure 7.1: 10cm VAS Scores for Patient Satisfaction with Care

7.5 Discussion

The purpose of this study was to explore the healthcare experiences of people with mild stroke. By exploring this phenomenon within the context of an RCT, novel findings were not only identified in regards to standard care, but also in regards to how additional support along the transitional continuum may alter experiences. Three major findings were identified: difficulties are experienced during the diagnostic period for people with mild stroke, there are gaps in post-discharge services, and follow-up was appreciated.

The participants in this study demonstrated difficulty with identifying their strokes. This aligns with recent quantitative data and helps to explain why such issues are occurring. Many of the participant's reported ambiguous symptoms that did not align with their thoughts of 'stroke'. This supports a UK study by Wolters, Gutnikov, Mehta, and Rothwell (2018), which identified that 37.6% of patients with mild stroke did not experience a F.A.S.T symptom and that correct perception of stroke symptoms for this population reduced after the F.A.S.T campaign. Labberton, Faiz, Rønning, Thommessen, and Barra's study (2018) also highlighted issues with the identification of milder strokes, demonstrating that more severe strokes are more likely to present earlier to hospital than milder ones. This might be because people with more minor symptoms are likely to deliberate on them and attribute them to other causes, when they do not align with the F.A.S.T acronym (Wolters et al., 2018). These issues are particularly worrying as stroke severity is reducing (Labberton et al., 2018), with the mild stroke population currently contributing substantially to the overall stroke population (Wolters et al., 2018). Therefore, public education campaigns may wish to consider raising awareness of symptoms that fall outside the F.A.S.T acronym (Wolters et al., 2018).

Findings from the current study also revealed that health professionals experience difficulty identifying mild strokes. This finding seems to be emerging in the mild stroke field. In a recent UK focus group study that incorporated people with mild stroke and health professionals, it was identified that inconsistencies in diagnosis and treatment of this population exist and further research was needed (Turner et al., 2018). Yoo and colleagues (2018) further substantiated this finding, identifying that rapid diagnosis can be delayed in patients with mild neurologic deficits. Whilst it is one thing to increase public awareness of more ambiguous symptoms of mild stroke, it is vital that health services are able to act accordingly when patients present. Educational programs may assist frontline emergency staff to recognise more subtle symptoms and the importance of rapid treatment (Yoo et al., 2018). The Australian Clinical Guidelines for Stroke Management 2017 endorses this through recognising that the assessment of stroke is a specialist area and close working relationships between emergency department staff and stroke specialists are necessary (Stroke Foundation, 2018b). Additionally, a participant in the current study emphasised the need for further investigation. This too is reflected in the guidelines, which highlight that whilst MRI scanners are limited in many facilities and have a longer imaging time than CT scanners, they are more sensitive and are particularly applicable to people with mild stroke (Stroke Foundation,

2018b). Overall, it seems that further awareness amongst health professionals is required in regards to mild stroke.

The second major finding of this study was that services for people with mild stroke are lacking in terms of ongoing access, coordination, secondary prevention, and information provision. Turner and colleagues' (2018) study supports this as it identified that there is a lack of follow-up care in this population. Moreover, they suggested that further research was needed in regards to effective follow-up pathways, the identification and treatment of impairments, information provision, and advice to patients (Turner et al., 2018). The Stroke Foundation of Australia stipulates that all people with stroke should be offered: the opportunity to discuss post-discharge needs, tailored information, and a comprehensive discharge plan to address needs prior to hospital discharge (Stroke Foundation, 2018b). However, people with mild stroke often are unaware of their needs during hospital admission and therefore their needs remain unaddressed, as demonstrated by the change in perceptions between 1- and 3- months in this study.

The last key outcome of this study was the appreciation that people had towards a formal support person along the transitional continuum. This is not surprising as social support has been shown to directly relate to post-stroke outcomes in the general stroke population (Stroke Foundation, 2018b), including better community participation (Beckley, 2007). The current study solidifies this finding in the mild stroke population. Furthermore, it has been identified in younger people with stroke that there is a need for more focus on nonmedical needs and care to be provided long after discharge (Morris, 2011). The current study confirms this finding within the mild stroke population as it was clear that support was appreciated during the 6 months post-discharge, with the support provided being focused on the person's holistic needs rather than their specific medical needs. Conclusively, ongoing formal support during the transitional period should be considered in the development of future mild stroke services.

7.5.1 Limitations

The small number of participants in this study limits the generalisability of results; however, the provision of participant demographics and details of the services provided enhances transferability. Generalisability is further limited by two participants receiving a novel intervention, but as the first two themes focus on standard services, and the third explicitly describes the differences in service experiences this limitation has been minimised. Finally,

this study was conducted in one hospital and health service in one location in Australia, and this must be considered when interpreting results.

7.6 Conclusion

The health service experiences of people with mild stroke are widely unknown. This study has contributed to the understanding of how this population experiences both standard and novel services. Three key findings were identified that require further attention. Firstly, the diagnostic period is full of ambiguity, for people with mild stroke and health professionals and research is needed to clarify and address these. Clinically, it is recommended that stroke physicians work with emergency medical professionals to enhance their understanding of ambiguous stroke presentations. Secondly, issues are continuing after hospital discharge in terms of access and use of health services to prevent and address ongoing issues. This supports the need for the development of ongoing, targeted services for the mild stroke population. Finally, the presence of an external support person enhances post-discharge experiences, and therefore should be considered by health systems when designing mild stroke services.

7.7 Chapter Summary

This chapter revealed the essence of healthcare experiences for people with mild stroke, in the context of two different models of care. Results of this chapter demonstrate that people with mild stroke experience issues with healthcare experiences during the entire transitional continuum, from diagnosis to 6-months post acute hospital discharge. This was observed through three themes: 'The difficult diagnosis', 'Standard care: good but not good enough' and 'A journey better not done alone'. Of particular note was the differing experiences of people in the 'standard care' and MiStrEnGTH intervention groups in regards to the level of support they reported, indicating the benefits of a formal support person during the transition period. The previous chapter and this chapter have both explored the experiences of people with mild stroke following acute hospital discharge. To further solidify the key support person experience, however, the next chapter will solely portray the experiences of key support people after their partner experiences a mild stroke.

Chapter 8: Supporting People with Mild Stroke: The Key Support Person Experience

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). The Lived Experience of Supporting People with Mild Stroke. *Scandinavian Journal of Occupational Therapy, Jul 2,* 1-10. doi:10.1080/1103828.2019.1633401

This chapter explores the experiences of four key support people in the lives of people with mild stroke, from a retrospective perspective at 9 months post acute-hospital discharge. Two key themes were identified in regards to key support persons' experiences. Firstly, there was a sense that the time they spent on their valued occupations and activities was minimised due to an increase in other activities as a result of their partner experiencing a mild stroke. This theme was titled 'Activities gained but time lost'. The second theme of this study was titled 'Subtle changes but big impacts' and reflects the emotional and behavioural changes that key support people observed in their partners, and the consequent impact this had on their relationship. Overall, this study has demonstrated that key support people are impacted when a spouse experiences a mild stroke.

The PhD candidate was primarily responsible for the design of this study, data collection and analyses, and writing of the article. Professor Louise Gustafsson contributed substantially to the article, assisting with data analyses, ensuring that all codes and themes were reflective of the raw data, and providing critical appraisal to writing. Associate Professor Petrea Cornwell participated in iterative discussions with the PhD candidate and Professor Louise Gustafsson and provided critical appraising to writing.

Contributor	**Statement of contribution**
Tenelle Hodson (candidate)	Conceptualisation of research design and question (70%) Data collection (100%) Data Analysis (70%) Writing and editing of manuscript (70%)
Louise Gustafsson	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (25%) Writing and editing of manuscript (25%)
Petrea Cornwell	Conceptualisation of research design and question (15%) Data collection (0%) Data analysis (5%)

Miss Tenelle Hodson – PhD candidate

	Writing and editing of manuscript (5%)

Miss Tenelle Hodson – PhD candidate

8.1 Abstract

Background: Mild stroke occurrences are rising and in order to comprehensively understand the experience of this health phenomenon, the context in which people with mild stroke live must be explored. Key support people are an important part of the lives of this population, but their experiences are yet to be fully understood.

Aims/Objectives: To answer the question: 'What is the essence of the mild stroke experience from the perspective of the key support person during the first 9 months after acute hospital discharge, in Australia?'

Materials & Methods: Qualitative study involving four key support persons at 9 months post their family member's mild stroke. Interpretative phenomenological analysis was used to analyse interview transcripts.

Results: Two themes were identified: 1) 'Activities gained but time lost', and 2) 'Small changes but big impacts'. The first theme portrays the increase in daily activity that key support people experienced due to caregiving related activities, which impacted on their occupational participation. The second highlights the impact that people with mild strokes' behavioural and emotional changes can have on key support people.

Conclusions & Significance: Whilst key support people generally return to their daily routines after a family member's mild stroke, some will experience increased time pressures and occupational disruptions. Health providers should prepare key support people for behavioural and emotional changes in people with mild stroke.

8.2 Introduction

Stroke is not an individual matter, but one that concerns both the person and their families (Burman, 2001; Lou et al., 2017). For instance, relatives and friends can become informal caregivers, providing help and assistance to the person with stroke, within the context of established roles such as wife, husband, child and parent (Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers face a state of transition after someone in their life experiences a stroke, due to life changes that must occur such as the adoption of extra roles within the family (Green & King, 2007; López-Espuela et al., 2018; Lou et al., 2017; Saban & Hogan, 2012). For spouses, this can spark a major marital transition altering reciprocity and support within a relationship (Anderson & Keating, 2018). Furthermore, associations between spouses' and people with stroke's emotional health and well-being have been established, with one impacting the other (Forsberg-Wärleby, Möller & Blomstrand, 2004; Kniepmann, 2014). It is therefore not surprising that previous research has identified that the partners of people with mild stroke are key to their rehabilitation and transitional experience and their experience must be addressed to enable people with mild stroke to have the best outcomes possible (Lou et al., 2017). The purpose of this study was to better understand the impact and experience of mild stroke on the spouse, or 'key support person'.

Knowledge to date about the key support person experience of people with mild stroke is largely based on research conducted in the wider stroke population, with limited studies identified specific to people with mild stroke. General stroke caregiver findings, however, indicate that the spouse of a person with stroke can experience increased strain and exhaustion from the new responsibilities adopted and the disruption to routines that occurs following a stroke (Anderson & Keating, 2018; Saban & Hogan, 2012). Furthermore, for some, they are forced to come to terms with a partner who has changed in regards to their behaviours towards them (Anderson & Keating, 2018; Gosman-Hedström & Dahlin-Ivanoff, 2012); which is likely to impact quality of life (Kniepmann, 2014; Gosman-Hedström & Dahlin-Ivanoff, 2012). The overall experience is also said to be dynamic with caregivers having changing needs at differing times following stroke (Forsber-Wärleby et al., 2004). These findings point towards a need to support stroke caregivers; however the differing needs of caregivers based on the severity of the family member's stroke is largely unknown.

Mild stroke is typically considered to be a cerebrovascular event that results in mild neurological impairment or disability (Green & King, 2007;2009). Approximately one third of the 56,000 people who experience a stroke each year in Australia are considered to have experienced a mild stroke as they are able to independently complete activities of daily living (National Stroke

Foundation, 2015b; Stroke Foundation, 2017). However, it must be noted that the ability to complete activities of daily living does not necessarily correspond with full recovery for people with mild stroke. Furthermore, whilst people with mild stroke may outwardly experience similar levels of deficits, the impact of the stroke needs to be considered in the frame of a life context resulting in varying experiences (Green & King, 2007). That is, it should not be presumed that a mild stroke occurs within a life that is devoid of other health conditions or contexts that also impact on health and wellbeing (Lou et al., 2017).

Three studies have explicitly explored the caring experience following mild stroke. A Canadian qualitative study followed 26 males with mild stroke and their wife caregivers during the first 12 months after discharge, through the use of semi-structured, telephone-interviews. This study identified that the couples experienced a sense of heightened vulnerability due to: a lack of information, uncertainty, threat of future stroke events, reduced control, and feelings of being stigmatised (Green & King, 2009). The study explored the caregiving experience within the context of the couple dyad and was narrowed in its scope by its focus on quality of life and caregiver strain. The findings were based on two open-ended questions asked as part of a questionnaire. Some exclusive caregiver findings were able to be identified though, including that they: engaged in hyper-vigilant monitoring of their husband's health and well-being which increased their own stress, anxiety and fatigue; adapted routines in order to enable their husband to participate; experienced alterations to elements of their physical, emotional and social lives; and experienced a loss of personal space and time (Green & King, 2009). Lou and colleagues (2017) explored the experiences of Danish people with mild stroke and their caregivers in the context of the couple dyad and early supported discharge; however, minimal findings were produced specifically in relation to the caregiver's experience. There is one study that was able to be identified in the literature that specifically explored the experience of caregivers of people with mild stroke and it focused on quality of life 3 months after hospital discharge (Tellier & Rochette, 2011). This Canadian study identified that caregivers experience: tiredness from attempts to juggle daily activities within the home, a lack of time for personal activities, financial concerns when their partners were unable to go back to work, changes in habits, future plans and perceptions of life, anxiety over the potential of their loved ones having another stroke, and reduced quality of life (Tellier & Rochette, 2011). Overall, these studies provide an indication that even when people with mild stroke require limited physical caregiving, they still need support that impacts those in their social network.

There is a need for continuing research to build on this knowledge and fully understand this experience and the implications across a range of health and social contexts. Bergström, Eriksson,

von Koch and Tham (2011) stated that the efficacy of interventions for caregivers of people with stroke needs attention and a new perspective on stroke research that explores elements external to the person with stroke is needed. It has also been suggested that further qualitative research is needed to better understand the causes of changes in well-being for spouses of people with stroke, especially within the first year (Forsberg-Wärleby et al., 2004) and the mild stroke population (Green & King, 2007). Consequently, the current study aims to address these gaps in the literature by using qualitative means to answer the question: 'What is the essence of the mild stroke experience for the key support person during the first 9 months after acute hospital discharge, in Australia?'

8.3 Materials & Methods

This was a qualitative study that utilised interpretative phenomenological analysis (IPA) and was completed in the context of a randomised controlled trial (RCT). The RCT aimed to identify the efficacy of an allied-health led, telehealth, stroke-specific self-management program (MiStrEnGTH – Mild Stroke Enhancing and Guiding Transition Home) in comparison to standard care. The current study was part of a larger program of qualitative research which aimed to understand the experience of mild stroke under the RCT's two different models of care. Recruitment for this qualitative component however, occurred in the final 7 months of RCT recruitment due to a delay in obtaining ethical approval. The qualitative program of research followed the tiered approach to IPA suggested by Smith and colleagues (2009). Consequently, this study occurred after a more in-depth exploration of the marital dyad experience of mild stroke and a study of people with mild stroke's experiences. IPA was chosen as it enables a thorough investigation of a phenomenon, allowing for the revelation of the 'essence' of an experience (Smith et al., 2009). Ethics approval for this study was obtained from the local ethics committees of the Hospital and Health Service in which it took place, and relevant universities (approval numbers: HREC/15/QPCH/18; 2016000021; GU: 2015/884).

8.3.1 Research Characteristics and Reflexivity

The choice of an IPA methodology was influenced by the authors' prior ontological and epistemological understandings, as well as the aim of the research study. From an ontological perspective, the authors aligned with a relativist ontology identifying that people's perceptions and interactions form reality, which is expressed through language (Finlay, 2011). The authors also believed that it is impossible for researchers to remain completely objective during research, as a result of their identity shaping the research process and findings, consequently supporting an interpretivist epistemology (Finlay, 2011). As a result, a reflexive excerpt has been developed by

the lead author below, in order for readers to understand how her background may have impacted the research process and findings.

The first author identifies as a Caucasian female of middle socioeconomic income and is from a metropolitan area in Australia. Her professional background is occupational therapy. These factors may therefore have influenced the questions she incorporated into her interview-guide, her interactions with participants, and her interpretation and coding of interview transcripts. Furthermore, as the first author has not experienced a stroke, nor has anyone close to her, her understandings of the phenomenon are purely from an academic and clinical perspective.

8.3.2 Participants

Key support people who were eligible for inclusion were consecutively recruited into this qualitative study during the later stages of the RCT. To be included in the RCT, key support people had to: have adequate language and cognition to provide informed consent, be responsible for providing informal assistance for a person with mild stroke, and be aged over 18 years. There were no additional inclusion criteria for this qualitative investigation. See Table 8.1 for participant details.

The IPA methodology recognises that understanding human phenomena can be complex and therefore studies using this methodology have smaller sample sizes (Smith, et al., 2009). A general rule of thumb for IPA researchers when determining sample sizes is to aim for three to six participants, which allows for similarities and differences to be identified between participants. It also ensures the researcher is not overwhelmed by the data generated (Smith et al., 2009). The current study recruited four participants in total, three of whom were key support people of people with mild stroke who received MiStrEnGTH. They too were eligible to receive MiStrEnGTH sessions.

Table 8.1: Participant Demographic Information

Participant Name	**Lynne**	**Susan**	**Ida**	**Pam**
Relationship to PwMS	Wife	Wife	Wife	Wife
Services Received	Standard	MiStrEnGTH Participated in: • 1st Session • 2nd Session • 3rd Session	MiStrEnGTH Participated in: • All 5 sessions	MiStrEnGTH Participated in: • 1st Session • 5th Session
Working Status	Volunteer	Non-Employed	Retired	Non-Employed
PwMS's Hospital LoS (Days)	2	7	2	5
PwMS's Age	68	80	73	64
PwMS's Stroke Type	Ischaemic R) Temporal	Ischaemic R) Middle Cerebral Artery	Ischaemic L) Thalamic	Ischaemic L) Medial Pontine
PwMS's Functional Status	Independent with Nil aids	Independent with Aids	Independent with Nil Aids	Independent with Nil Aids
PwMS's Work Status	Retired	Retired	Retired	Working Full-Time

*PwMS: Person with Mild Stroke; MiStrEnGTH: Mild Stroke: Enhancing and Guiding Transition Home; d/c: Discharge; LoS: Length of Stay

8.3.3 Interventions

Standard care, as received by all people with mild stroke included medical care within the acute stroke ward and all or any of the following: stroke education, a general practitioner (GP) referral and discharge report, a follow-up appointment at an outpatient clinic, peer support group information provision for the person with mild stroke, or a referral to or information provision on local community-based support programs and services.

In addition to standard care, MiStrEnGTH participants received a tailored program during the initial 6 months at home following hospital discharge, which consisted of five telephone calls provided by an allied-health professional (AHP). Key support people had the option of participating in these phone calls, separately to the person with stroke. The first three telephone calls occurred at 1-, 4-, and 8- weeks post discharge, with the timing of the final two phone calls being negotiated between the AHP, the person with stroke and the key support person as required. Each telephone call utilised motivational interviewing and shared decision making to guide: reflections on areas of change, areas of progress and achievements made; identification of areas that had been impacted, current supports and unmet needs; goal planning, where participants learnt how to develop their own goals and action plans to achieve these; and an educational component where the therapist assisted participants to identify ways of obtaining information. Participants with stroke and their key support people were also provided with the AHP's contact details if they needed assistance between telephone sessions. See Table 8.1 for details of key support people's engagement in this program.

8.3.4 Procedures

Potential participants were identified by the RCT project officer, who obtained written informed consent for them to participate in qualitative interviews. After consent was obtained, the lead qualitative researcher (TH) contacted potential participants at approximately 8- to 9- months post the person with mild stroke's discharge and organised interviews. Participants were interviewed at approximately 9 months after the person with mild stroke had been discharged from hospital following the stroke event. The interview timepoint, i.e. 9 months, represented a 3-month follow-up after the cessation of MiStrEnGTH. All semi-structured interviews were completed in the participants' homes and lasted between 40 and 74 minutes. Interviews were audio-recorded and transcribed verbatim. All participants have been given a pseudonym to comply with confidentiality protocols.

An interview guide steered semi-structured interviews and was developed from recommendations outlined by Smith and colleagues for IPA studies (2009). Consequently, the

questions prepared were of an open and expansive nature, starting with a question that enabled the participant to recount a relatively descriptive experience so that they were encouraged to talk at length (Smith et al., 2009). Questions were decided upon after an iterative process of development, inclusive of multiple drafts, a trial interview and discussions amongst the three researchers (Smith et al., 2009). In total, there were three open-ended questions: 'Tell me about how you perceive the stroke affected [person with mild stroke]', 'Can you tell me about how [person with mild stroke] having the stroke affected your daily life?', and 'How has your experience been with health services?'. Prompts, derived from the literature, were given in the following areas when exploring these questions: daily activities, home life, employment, driving, physical and emotional health, lifestyle habits, and personal relationships. These areas were sequenced from least to most sensitive in order to enable the researcher to formulate rapport before asking participants more personal questions.

8.3.5 Data Analyses

An IPA approach was undertaken on the data obtained in this study (Smith et al., 2009). This involved TH reading through transcripts multiple times in order to become immersed in the data (Finlay, 2011), with subsequent line-by-line coding and noting of initial interpretations (Finlay, 2006; Smith et al., 2009). Once this had been completed, TH presented initial codes to the other members of the research team (LG & PC) and an iterative discussion took place where codes were formed into emerging themes. TH then completed a second round of analysis and presented refined themes and codes to LG, and the two researchers further discussed the themes until the two superordinate themes were identified. Both LG and TH then completed final, separate reviews of the data to ensure that themes were representative of participants' accounts. Efforts were made throughout this process to achieve trustworthiness. For instance, TH and LG both performed negative case analysis in order to improve credibility of the research, actively searching for participants' accounts that did not align with emerging themes and adjusting themes until all accounts were included (Lincoln & Guba, 1985). Furthermore, an audit trail was kept at all times during the research, inclusive of raw data, data reduction, analysis products and data reconstruction and synthesis products which assisted with the achievement of dependability and confirmability (Lincoln & Guba, 1985).

8.4 Results

Results of this study foreground the essence of the mild stroke experience for four key support people who were all women and aged in their sixties and seventies, at 9 months post hospital discharge in an Australian setting. Additionally, this study has been able to identify this experience,

irrespective of differing health services provided to either the person with mild stroke or their key support person. Whilst it appears that overall participants in this study had adapted to their new situation and had fallen into a new rhythm of life, two themes were identified that related to changes which occurred during the transition continuum for these participants: 'Activities gained but time lost' and 'Subtle changes but big impacts'. These themes were identified within the context of the person with mild stroke experiencing a number of changes related to the stroke event, which were different for each individual but included: altered physical functioning, fatigue, cognitive challenges, and emotional disruptions. Furthermore, on an activity-level people with mild stroke also experienced disruptions to driving, work, and participation in leisure activities. These issues continued throughout the first 9 months after the mild stroke for some, but for others noticeable changes were only present early on, or at differing points along the transition continuum.

8.4.1 Activities gained but time lost

This theme reflects the value key support people placed on their personal time, but also the time pressures that were present following the mild stroke as a consequence of the additional activities they needed to complete. When individuals were able to maintain some of their valued occupations, it appeared that their overall experience was better and they were able to cope with the additional demands on their time. However, those who were not able to do this appeared to experience difficulty along the transition continuum.

One occupation that increased due to additional demands during the initial period following hospital discharge was driving. The increase in driving was experienced differently for each individual. Ida and Pam reflected on being self-conscious and staying within the parameters of driving that they felt comfortable with.

> *'Well I didn't – I didn't really mind, yeah. I knew that [husband] didn't like being a passenger so it was kind of a little bit more um, conscious, self-conscious driving. You know like-Someone that might criticise me for doing the wrong thing.'* Ida

For Lynne, her driving abilities were impacted by her own experience of fatigue. On the other hand, whilst Susan admitted that her driving activity increased following her husband's mild stroke, she reflected that she quite enjoyed this and only saw needing to drive him places as a minor inconvenience.

> *'…like I had to take him to the doctor's and I don't, I just want to sit at home, you know, but I mean, they're such little things that they don't matter.'*

Additionally, Susan emphasised the appreciation she had for her husband being alive after the stroke and she indicated that this made additional caregiving activities acceptable. Other activities

that spouses took on following the stroke included: monitoring of the person with stroke's stress levels, organisation of weekly medications, gardening activities, and entertaining the person with stroke.

An unexpected area of change that occurred for three out of four of the participants was in regard to travel. For Susan, this meant that her overseas travel plans were cancelled altogether in order to be able to be there for her husband.

> *'…I missed out, which is perfectly fine, I was going to go to Israel with my sister when [husband] had his stroke, um, so I didn't do that.'*

Ida on the other hand discussed the alterations she had made to her overseas holiday plans as a result of travel insurance requirements that restricted her husband from being covered for health procedures in some countries.

> *'…There was a big problem with getting comprehensive travel insurance and medical cover for [husband]. He had the full cover and then when he had the mild stroke we had to let the insurance company know and they wouldn't cover him for any of his medical problems. So, we could only go to the countries that have reciprocal agreements with Australia in terms of health cover.'*

Key support people reported that their experience of travelling was now different, changing as a result of stroke-related difficulties experienced by the person with mild stroke. For instance, Ida's husband now experienced short term memory issues, which impacted on his ability to contribute to day to day organisation whilst traveling therefore leaving this responsibility to her. Lynne had a similar experience to this, identifying that their most recent trip had been more stressful than previous ones as a result of her being solely responsible for planning.

> *'…We went on a holiday, right, to South America. [Husband] normally has control of the passports, the paperwork, the tickets – everything. And he normally does all that, and, and directions. I organise it all. This time, I had to do the whole lot. He just didn't know what papers were needed. He didn't know what – in the airport he, if he wandered off, he would get lost…It, yeah it's just made it very, very hard for me because I had to do everything.'*

Evidently, due to the complexity of travel and difficulties experienced by people with mild stroke, the enjoyment that key support people once had when planning and engaging in travel had altered.

Key support people also reflected on the need for 'me time' during this period and it was clear that those that were able to prioritise and achieve such time, were happier with their overall transition experience. For instance, for Ida the hobbies and activities that she participated in by

herself were not impacted and she projected a sense of joy when discussing these. Likewise, Susan discussed staying up late each night after her husband had gone to bed in order to watch TV and just be alone.

> *'…I've always got someone around like, when he goes to bed I can actually have time by myself.'*

In contrast, Lynne was unable to maintain her own occupations after her husband experienced his mild stroke and it became clear that he occupied more and more of her time. This was observed in the context of cooking which Lynne emphasised as an occupation that she highly valued, but one her husband now did not let her do by herself.

> *'Cooking was mine. I always cooked because I'm a good cook and I love cooking. And he never sort of worried. Yeah, now he sort of wants to – I don't know. It's funny. Really weird.'*

Additionally, on days when Lynne was volunteering at a community organisation, her husband would arrive to pick her up an hour early. Lynne portrayed this as an intrusion on this meaningful occupation. She also reflected on no longer having time for her hobbies such as glass painting, making photo books and collecting stamps. In an attempt to gain this time back to herself, Lynne suggested her husband volunteer somewhere one day per week however he showed a lack of interest in this idea. Pam similarly discussed issues with her husband's ability to occupy his own time and how the stroke had given her a chance to see what retirement would be like, indicating fear around him potentially intruding on her time.

> *'-you know, like he can fill his time with other things. But when he's got that seven days, it's 'what am I going to do?' sort of thing, so I'm a little bit sort of 'Oh God, what's it going to be like?' sort of thing.'*

Overall it appeared that spouses experienced and, for some, continued to experience changes to how they spent their time during the nine months following their husband's stroke, however the impact of this was reduced if they were able to participate in their own valued occupations.

8.4.2 Subtle changes but big impacts

A noticeable theme throughout the interviews was the impact that stroke-related behavioural and emotional changes had on key support people's experiences in the 9 months following hospital discharge. Some key support people observed that their husbands' emotions had heightened. This was seen through them becoming upset more easily and anxious when things did not go to plan. For Susan this resulted in her husband wanting her around more and her needing to make this time for him.

'…What happens is that he panics now and if anything goes wrong, he'll panic and when he's not feeling a hundred per cent he doesn't want me out of his sight either…'

Ida and Pam also reflected on this and discussed the need to be patient and more available for their husbands, whether it be because they were upset or just feeling a bit low.

'…Well we're always very supportive. Just had to be a bit more patient I suppose [laugh] with some of the things, that was going on, yeah.' Ida

For Lynne on the other hand, her husband's changes were of a more behavioural nature, and she reflected on her experience of him becoming angered easily. This had resulted in relationship stress and Lynne had threatened to leave the relationship if he did not alter his behaviour.

'…He gets really, really bad tempered. I told him the other night if it wasn't for the fact that I loved him, I would have left him…Because he does – he has a very short temper now.'

However, key support people also noticed positive changes in the person with stroke. For instance, Pam spoke of how she had observed her husband alter his approach to work and a consequent reduction in his stress levels.

'*…yeah he's not pushing himself and, you know, worrying about meeting targets or racing around finding new clients or anything like that. It's just "well I do what, I do my job and that's, that's it, so.'*

All participants reiterated that these changes were subtle and would not be easily observed by others.

For the key support people whose husbands' emotional and behavioural changes lingered, it was identified that further support in this area would be appreciated. Ida discussed this in terms of her husband obtaining more assistance with the emotional impact of the stroke.

'*…he feels that, you know, a bit more of the psychological support would be really good…'Cause, you know, it's something that obviously does affect you that way. You know, you can sort of get pretty stressed about the whole thing and just how to deal with it and-. Or just someone to just talk to, you know, and get it all kind of out if you're worried about things that maybe a little bit irrational or something.'*

Lynn, however, highlighted that this kind of support could also be appropriate for key support people, stating: '*I'm full of whinges, aren't I?...But sometimes it's good to talk about it.'*

Overall it appears that the behavioural and emotional changes observed in the person with mild stroke had the most impact on key support people, over and above any physical changes that may have occurred.

8.5 Discussion

This study aimed to explore the experience of key support people of people with mild stroke, during the first 9 months after acute hospital discharge in an Australian setting. Whilst participants reported that their lives had predominantly returned to as they were pre-stroke, two key findings were identified in relation to how the mild stroke had altered their lived experiences. Elements of these findings will now be discussed in terms of the wider literature and directions for future research and practice.

Firstly, one of the findings in theme one, 'Activities gained but time lost', centred around participants' increased involvement in driving activities as a result of the person with mild stroke's driving restrictions during the first month post stroke. This reflects findings in the wider disability literature where driving disruption has been found to impact family members, as well as the individual themselves (Liang, Gustafsson, Liddle & Fleming, 2015). For caregivers, the adoption of the primary driver role within the family can reduce the time available for them to participate in their own occupations (Liang et al., 2015; Liang, Fleming, Gustafsson, Grffin, & Liddle, 2017). Examples include, interruptions to their ability to work, exercise, and participate in leisure activities (Liang et al., 2017) all of which are essential to maintain overall health and wellbeing. Whilst the participants in the current study were not working or raising a family at the time of their partners' strokes, the mild stroke population is commonly younger than the general stroke population (Wolf et al., 2009). This occupational change within the family therefore has the potential to create a great impact on their daily life and family functioning (Liang et al., 2015;2017), even if it is short-term. As a result, it is necessary for health professionals to engage in discussions with family members around the implications of driving disruption, such as time off work, and actively prepare and assist them with this (Liang et al., 2015; Liang, Liddle, Fleming & Gustafsson, 2016). However, health professionals have previously expressed a lack of confidence in their knowledge and skills to address the topic of driving disruption (Liang et al., 2015). Consequently, further research and work is needed to assist health professionals and services in supporting key support people during periods of driving disruption after health events, such as mild stroke.

In addition to an increase in driving participation early after the stroke, key support people also reported a general increase in the number of activities that they needed to complete each day within the first theme. The impact that this increase in activity has on the lives of key support people must be discussed. Green and King (2007) previously identified that caregivers of people with mild stroke often feel belittled by the assumption that they can

easily put their life on hold in order to suit their partner's needs. More broadly, and similar to findings around driving disruption, the increase in time spent in activities after a spouse's stroke has been linked to caregivers needing to reorder their priorities (Burman, 2001; Kniepmann, 2014). When caregivers do find time to themselves they also report being disrupted (Gosman-Hedström & Dahlin-Ivanoff, 2012; Green & King, 2007; Saban & Hogan, 2012) aligning with the sentiments of one of the participants from this study. Carers of people with stroke have previously discussed the importance of gaining time to participate in meaningful occupations, reporting that life is more satisfactory when they are able to find time to themselves (Gosman-Hedström & Dahlin-Ivanoff, 2012). Findings from the current study support this within the mild stroke population, with key support people placing great importance on participating in their own occupations outside those related to caregiving or which involve the person with mild stroke as well. Consequently, healthcare providers should consider how they can assist key support people of people with mild stroke to maintain their engagement in meaningful occupations.

A unique finding that was revealed from the first theme was that three of the participants had their travel plans deferred or altered as a consequence of their partner experiencing a mild stroke. Most studies conducted in relation to stroke and travel are focused on community mobility and walking ability (Barnsley, McCluskey, & Middleton, 2012; Carlstedt, Iwarsson, Stähl, Pessah-Rasmussen, & Lexell, 2017; Logan et al., 2004). To the authors' knowledge limited research has been conducted in relation to general travel and issues related to travel that are not a direct consequence of mobility difficulties. Indeed, this has been stated in the wider disability literature where it has been identified that there is minimal literature on travel related to specific illnesses (Bauer, 2018). This is particularly pertinent to the mild stroke population who are often younger and engaging in activities such as international travel whether it be for work or leisure purposes (Wolf et al., 2009). Some findings from the general stroke research regarding community mobility however, may be transferable to general travel. For instance, people range in their confidence levels in terms of travelling which is often influenced by their social sphere, and the person's emotional disposition can have an impact on their engagement in outdoor travel (Barnsley et al., 2012). The second of these points relates directly to key support people as it indicates that they may be able to assist their partners in being confident to engage in travel; however, it seems health providers can also assist by monitoring people's emotional dispositions. Extending further into the general health sphere, findings from dementia friendly air travel research may be

considered for people with mild stroke, when providing recommendations. For instance, the need to plan ahead and consider factors such as the location of the person's flight seat and the selection of flights that arrive and leave during quiet travel times may reduce stress when travelling (O'Reilly & Shepherd, 2016). Given that health professionals have been found to act as 'gatekeepers' to people's engagement in travel after stroke (Barnsley et al., 2012) this may be a key area of life that health professionals should consider discussing, especially in the mild stroke population. For instance, to fully meet the needs of people with mild stroke and their key support people, their views and experiences should be sought in areas such as: the receipt of travel health information, issues that arise when preparing for and engaging in travel, travel in countries with reduced resources, impact of travel on wellbeing (Bauer, 2018), and the impact of mild stroke on travel insurance. This research should optimally be conducted from a multidisciplinary perspective, where both health professional and tourism researchers contribute to the development of new knowledge (Bauer, 2018).

Finally, the most significant finding from theme two, 'Small changes but big impacts', was the change that key support people observed in the person with mild stroke's emotions or behaviours. These changes resulted in the key support person either needing to be more patient with the person with mild stroke or tolerate altered behaviours. Whilst not a universal experience, for some these adaptations were ongoing and impacted on daily life. Emotional and behavioural changes after stroke are often made evident much later in the transitional continuum compared to physical impairments (Forsberg-Wärleby et al., 2004). Due to the rapid discharge of people with mild stroke, this area of need may go unaddressed. By taking time to educate key support people about 'hidden' impairments prior to and after hospital discharge it may assist them with interpreting changes in their partners' behaviours, leading to a better understanding of such changes (Forsberg-Wärleby et al., 2004; Gosman-Hedström & Dahlin-Ivanoff, 2012; Knipemann, 2014). Additionally, clear communication between acute healthcare professionals and GPs may be able to assist with ensuring needs are met (Gosman-Hedström & Dahlin-Ivanoff, 2012; Greeen & King, 2009). This could, for instance, include acute hospital teams providing GPs with a summary of the information that has been provided and screening for key support people that may require increased support (e.g. those with numerous other life-stressors). Ultimately, key support people of people with mild stroke are impacted by the stroke event and it is the duty of the health profession to ensure their needs are met in order to ensure a positive transition for them and the person with mild stroke back to daily life.

8.5.1 Limitations

This study has some limitations that need to be considered when interpreting the results. Firstly, the study relies on participants recollections of the 9 months prior to data collection and therefore are open to recall bias. Secondly, only four participants from one location in Australia participated in this study limiting its generalisability. Transferability however, may be achieved by reading the thorough detail provided in regards to the context in which the study took place and by studying participant demographic details. The use of one-off interviews reduces the depth of information obtained in this study. Furthermore, whilst IPA favours the use of interviews, additional data collection methods such as participant observation could have helped in contextualising and enhancing findings (Smith et al., 2009). Finally, the participants in this study were part of an RCT and therefore three were receiving a novel intervention to assist people with mild stroke and their key support person. The participants' involvement in the RCT also meant that the manner in which they were recruited was not in line with the usual approach for a qualitative study which may have restricted the kind of participants that became involved in the study.

8.6 Conclusion

Key support people are an important part of the lives of people with mild stroke and impact on their overall outcomes and transition experiences. This study has contributed to understanding the key support person experience, specifically in terms of ongoing implications. Findings indicate that key support people experience an increase in activity levels as a result of a family member experiencing a mild stroke and this impacts on their occupational participation. Emotional and behavioural changes observed in the person with mild stroke were also found to impact on key support people's experiences. Consequently, health services and professionals should aim to assist key support people of people with mild stroke in preparing for potential occupational disruptions and educate and support them with 'hidden' impairments that the person with mild stroke may experience.

8.7 Chapter Summary

This chapter has explored the key support person experience of people with mild stroke. It has helped to extend findings identified in Chapter 5 by including more individuals' experiences. The key findings of this chapter highlight that even though the impact of a mild stroke may not be as observable as more severe strokes, it can still affect key support people's daily lives. In particular, this chapter has emphasised that the key support person's time becomes more monopolised by the person with mild stroke and that the person with mild stroke's behavioural and emotional changes

have an effect on the key support person. The following chapter will bring together the findings from each of the results chapters and will discuss avenues for future progress in meeting the needs of people with mild stroke and their key support people.

Chapter 9: Discussion

This program of research aimed to explore and identify the essence of the transition experience for people with mild stroke and their key support people after acute hospital discharge. Additionally, it sought to understand this experience within the context of two models of care, specifically 'standard care' and MiStrEnGTH. As with any qualitative investigation, there was no hypothesis and consequently the findings produced were of an exploratory nature. This chapter will start with a summary of the findings from each of the studies incorporated in this program of research. A general discussion of the findings within the context of the most recent evidence base, particularly from within Australia will then follow. A schematic representation of these findings will then be presented to synthesise and increase their utility. Following this, three separate discussions will take place guided by the schematic representation: 1) Implications for Health Services, 2) Implications for Clinical Practice (inclusive of case studies) and 3) Implications for Future Research.

9.1: Summary of Research Findings & Implications

9.1.1 Study 1

The first study aimed to identify the experience of transitioning from hospital care to the community following a mild stroke for a spousal dyad in the first 9 months after acute hospital discharge. This study allowed an in-depth exploration of one spousal dyad and for the minutiae of the mild stroke transition experience to be revealed on an individual level, before building on this and moving onto broader understandings in subsequent studies. By exploring the phenomenon on such an intricate level the findings of this study were able to highlight the impact that context can have on the transition experience following a mild stroke. From the outside, the couple in this study were reasonably well positioned to cope with the impact of a mild stroke. They had a stable financial situation and relationship and were in a stage of life where they were able to accommodate changes. Furthermore, their wider social context assisted with their relatively smooth transition experience. However, they still experienced some changes following the mild stroke even within this context. Two major themes emerged from this data that were temporal in nature: *The* 'Unexpected, Undesirable & Short-Lived' and 'The New Normal'.

The first theme revealed the changes that occurred during the initial month at home for the couple. While short-lived, a sense of confusion, adjustment and adaptation was evident during this period, which resulted from a number of factors. These factors included: being overwhelmed by the amount of information provided during this time, the disruption to the person with mild stroke's engagement in work and driving occupations, and the constant presence of the person with mild

stroke in the home. The second theme illustrated how there was a feeling of returning 'back to normal', which was gradually developing during the first 9 months post-discharge. Changes that remained during this period however, included: the key support person's increased awareness of her husband's health and the person with mild stroke's engagement in preventative practices, changed approach to work and continued altered limb functioning. Both participants were quite accepting of these changes, demonstrating flexibility and adaptability. This acceptance was assisted by comparing their situation to those who may have experienced more significant strokes, the presence of new health conditions, and receiving a level of support that met their needs.

The findings align with previous research (Green, 2007; Green & King, 2009) highlighting that there are commonalities that occur in the first few weeks at home for spousal dyads following a mild stroke. The impact of new health conditions on the mild stroke experience adds new information to the mild stroke knowledge base. Furthermore, this study identified that information provision can sometimes be overwhelming after a mild stroke.

9.1.2 Study 2

Study two aimed to build on the findings from study one, however with a specific focus on the experiences of the person with mild stroke. It was directed by the question 'How do people with mild stroke understand their experiences in the first 6 months after hospital discharge?'. In order to answer this question it followed the lives of five individuals across the first 6 months after hospital discharge. Two themes emerged to describe how different participants experienced their transition.

The first theme, 'Understandings and representation of stroke' emphasised how societal understandings of stroke and the person's own life events impacted on the way they experienced their stroke. This theme had two subthemes. The first, 'Society defines the stroke experience' reflected how participants appeared to have a pre-conceived idea of what stroke should look like. For instance, their perception of stroke was that it was a condition that occurs in older adults and one that should have observable consequences. This resulted in participants feeling like their repercussions were easier to live with and younger participants experiencing more of a 'shock' relating to the stroke event. The second sub-theme, 'The past determines the present' represented how past experiences, especially with health conditions shaped participants views of their mild stroke. For some, if past health conditions were comparatively 'worse', the mild stroke appeared easier to adapt to. However, for others the mild stroke was experienced as worse than previous conditions and the changes that came as a consequence of it disrupted the person's life. Finally, past experiences also appeared to provide participants with personal qualities that assisted them with

being more adaptable to stressful life events. Personal qualities included: hope, flexibility, perseverance and defiance.

The final theme, 'Underlying relationship dynamics' revealed illustrated how the experience of mild stroke was influenced by existing relationship functioning. Notably, participants who appeared to have solid foundations reported strengthening of their relationships. However, for those whose relationships were more complex before the mild stroke, it appeared that these unravelled as changes in their everyday lives occurred.

It was clear that participants thought that the repercussions of their stroke did not warrant as much attention because they were not easy to observe. This indicates that public knowledge around the less observable implications of stroke is lacking and in order for people with mild stroke to receive necessary support, greater awareness is needed. The differences in experiences of participants in this study appeared to be linked to their previous life and health experiences and highlights the truly individual nature of the mild stroke experience, which may make it hard for a particular intervention to cater to the needs of all individuals in this population. Finally, the need to consider previous relationship dynamics and how this may affect the quality of support that the person with mild stroke receives should also be noted.

9.1.3 Study 3

The third study in this research program specifically targeted people with mild stroke's experiences of health services, and therefore extended findings of the second study. Consequently, it aimed to answer the question 'How do people with mild stroke perceive their experience of stroke-related healthcare services?'. The same five participants were followed along the first 6-months after hospital discharge to explore this question revealing three themes: 'The Difficult Diagnosis', 'Standard care: good but not good enough', and 'A journey better not done alone'.

'The Difficult Diagnosis' described the issues that participants had in obtaining a mild stroke diagnosis. Participants reflected that they did not initially associate their symptoms with stroke, as they were quite ambiguous. Additionally, according to participants health professionals also appeared to experience difficulty providing a diagnosis, with participants reporting that they were sent home or not provided with further assessments that would identify the stroke. Consequently, this theme builds on the sub-theme 'Society defines the stroke experience' from the second study, identifying that knowledge around mild stroke and its symptoms may require improvement in both social and health environments.

The second theme, 'Standard care: good but not good enough' highlighted the appreciation that participants had for stroke services received but also identified areas that needed improvement.

For instance, co-ordination of services appeared to be disjointed resulting in missed opportunities for follow-up and support. Furthermore, health services appeared to provide information in a way that enforced what people should not do instead of what they could do, framing recovery in a somewhat negative manner. Finally, some areas of information provision appeared to need more attention, for instance: accessing pathways of care, financial support and intimacy.

The final theme in this study indicated that having an ongoing connection with health services during the transitional period increased feelings of security. For people who received MiStrEnGTH, this person was the allied health professional that contacted them throughout the 6 months. Standard care participants on the other hand appreciated that somebody was 'checking in', referring to the RCT's researchers.

Health professionals, particularly those in the community and emergency departments from the perspective of participants appeared to experience some difficulty with identifying and diagnosing mild stroke and this finding should be explored further as it may have implications for the expediency with which this population is treated. It also appears that coordination of services and information provision following hospital discharge for people with mild stroke requires improvement. The addition of ongoing contact with health services during this time was viewed positively and should be considered in further programs targeted at people with mild stroke.

9.1.4 Study 4

The final study aimed to build on findings from the first study by exploring the key support person experience further. To do this, the study included more individuals in order to develop a broader perspective of the experience. Consequently, the research question that was used was: 'What is the essence of the mild stroke experience for the key support person (KSP) during the first 9 months after acute hospital discharge, in Australia?'. Two themes were identified: 'Activities gained but time lost' and 'Subtle changes but big impacts'.

The first of these themes highlights the extra activities that key support persons completed, especially in the immediate period following the stroke. As a result of an increase in these activities, participants appeared to lose time for their own meaningful occupations. If key support persons were able to gain time to themselves and maintain their meaningful occupations, it appeared that they were able to cope better. Moreover, an unexpected occupational change that occurred for three of the participants was in relation to travel. This was observed by key support persons needing to make alterations to, or cancel their travel plans and take on extra responsibilities when travelling.

The second theme, 'Subtle changes but big impacts' explored the behavioural and emotional changes that key support persons observed in their spouses. Participants reiterated that these

changes were subtle and not easily identified by those outside the home. However, they did think that support was needed for either their husbands and/or themselves to cope with these changes.

Whilst the participants in this study had the ability to assist their spouses during the immediate period after the stroke with extra activities, such as driving, it is known that a large proportion of the mild stroke population is of a younger age (Wolf et al., 2009). Consequently, key support persons may be working at the time of their family member's mild stroke and this should be considered by health professionals when determining need for extra support or services. Further research is needed however to explore this phenomenon. Findings surrounding the disruption to travel for people with mild stroke and key support persons in this study also warrants further attention. Currently, stroke research focuses on community mobility or walking ability and little research has occurred in relation to people's ability to travel nationally or internationally. This could be particularly pertinent to the mild stroke population who may be travelling for family holidays or work. Finally, key support persons should be better prepared for the 'hidden' impairments that can occur after hospital discharge in people with mild stroke.

9.2 General Discussion

Findings from this program of research build upon the current understanding of the experience of mild stroke in Australia and suggest a need for targeted services. This is consistent with recent results from the wider stroke literature, which have identified that people with stroke or TIA have considerable long-term unmet needs after discharge (Olaiya et al., 2017). The current program of research emphasises however, that the individual needs of people with mild stroke are not easily identified and a range of factors need to be considered when determining the impact of a mild stroke for each person. This ambiguity may be a contributing factor to the current inequity in access to stroke services that exists for people with mild stroke in Australia (Finch et al., 2017). By exploring the experiences of people with mild stroke under current health practices in Australia through a qualitative approach, the findings from this program of research are also able to contribute to discussions about what is working well and what requires further attention in order to meet the needs of this population. Additionally, by exploring people's experiences of the MiStrEnGTH program in comparison to standard care it was revealed that this population appreciates ongoing support following acute hospital discharge.

The multi-dimensional nature of the mild stroke experience has been emphasised in this program of research, in particular those influences that extend beyond the neurological event and its direct consequences. It should be noted that this finding may also apply to people with moderate to severe stroke, however the differences in subsequent service provision may result in differing

experiences. For instance, people with moderate to severe stroke may be more likely to receive additional services and support through rehabilitation services, which may assist them to navigate the transition period and adapt more readily. However, this is based on speculation and a comparative study between the experiences of people with mild stroke versus those with moderate and severe strokes would need to be completed to illuminate this phenomenon further. For instance, Rochette and colleagues (2006) offer a different perspective suggesting that people may be able to better adapt after more severe strokes as improvements in their functioning are more explicit compared to those with mild stroke whose difficulties, whilst not as severe, may remain constant. Nonetheless, the current findings add value to the knowledge held in the stroke field, which has traditionally focused on the exploration of functioning and disability factors (Hoyle, Gustafsson, Meredith, & Ownsworth, 2012).

The mild stroke experience appears to be the result of an interplay of: the effects of the stroke, health services provided, societal views of stroke, the person's past experiences and personal qualities, and relationship dynamics with family members. A 'one size fits all' approach will therefore most likely not achieve optimal wellbeing and quality of life for the mild stroke population and is a factor that must be taken into consideration when designing services for this population. Whilst current findings from the general stroke field have started to provide indications towards some of these contextual factors, they are yet to provide a comprehensive overview for people with mild stroke. For instance, Australian stroke researchers have recently identified that functional deficits after stroke are based on more than just the type or severity of stroke, but also incorporate other factors such as comorbidities (Olaiya et al., 2017). A schematic representation of the current study's findings (Figure 9.1) has therefore been developed in order for health services, professionals and researchers to use and consider when working with this population in the future.

9.3 Schematic Representation of Findings

This representation of findings is intended to lay the foundations for future work and should be built upon by other clinicians and researchers in the field. Consequently, it is not concrete or definitive in nature. Below, the components of the schematic representation are described to assist with interpretation. Whilst these descriptions are brief, the concepts will be explored further in the discussion that follows. This schematic representation of findings incorporates all elements of the World Health Organisation's (2002) International Classification of Functioning, Disability and Health and aligns with Schlossberg's (1981) model for analysing human adaptation to transition; however, it provides specific factors to consider for people with mild stroke.

9.3.1 Potential Stroke-Related Changes

Changes in the person that are a direct result of the mild stroke event may include: altered emotions, behavioural changes, limb weakness, speech issues, cognitive issues, and fatigue. These changes, which were observed within the participants in this study are supported by the mild stroke evidence-base further solidifying this element of the schematic representation of findings. For instance, a number of emotional sequelae have been reported in the mild stroke literature including: feelings of embarrassment, insecurity, shame, stress, panic, fear, depression, loneliness, reduced self-esteem, irritability, and anger (Carlsson et al., 2004; Green & King, 2007). Subtle physical changes have also been reported previously and include changes in limb functioning, but also extend beyond this and include general deconditioning (Hildebrand et al., 2012), facial weakness, dysarthria and sensory loss (Edwards et al., 2006; Tellier & Rochette, 2009). Consequently, the current program of research only reports a limited number of physical changes that may occur after mild stroke, and when considering this area of the schematic representation of findings, previous and future findings from other researchers should be considered. Furthermore, for clinicians it is important to understand the individual's unique mild stroke presentation. In regards to cognition, Jacquin and colleagues (2014) and Wolf and colleagues (2011) have reported that between 47.3% and 66% of their study participants experienced cognitive difficulties on some level. Finally, fatigue is reported extensively within studies of people with mild stroke (Carlsson et al., 2004; Green & King, 2007; 2011; Gustafsson & Turpin, 2012; Hildebrand et al., 2012; Kristensen et al., 2014; Taule & Råheim, 2014). What was apparent in this program of research was that these elements of mild stroke were not always easily identifiable during participants' hospital stays. Indeed previous research has identified that acute hospital measures struggle to detect issues in this population (Green & King, 2010; O'Brien & Wolf, 2010; Tellier & Rrochette, 2009; Wolf et al., 2009; Wolf & Koster, 2013).

9.3.2 Life Experiences

Understanding a person's experience with previous health conditions and life experiences, as well as their personal attributes, characteristics and values may assist health professionals to understand the person's individual ability to adapt to changes present after a mild stroke. This conclusion was drawn from findings, however aligns with theories surrounding transitional experiences in general. As discussed in Chapter 2.2, the impact of a transition is individual to each person as it depends on how they appraise the transition, the context in which the transition occurs, and the changes it creates (Glass & Maddox, 1992; Goodman et al., 2006). Consequently, if a person perceives the mild stroke to be a 'minor' event and is at a stage of life where it does not create major change they

might experience a relatively smooth transition. Conversely, if the stroke event is interpreted as a significant health event, causes the person to take time off work and results in ongoing cognitive and physical changes it may have a large impact on the person's life and should be considered for ongoing stroke services.

9.3.3 Relationships

Gathering information about the functioning of the person with mild stroke's relationships prior to their stroke can identify the level of support they are likely to have as they transition home and whether there are other stressors that might need addressing to support a smooth transition. If more complex relationships are identified, for instance, it may be appropriate to provide extra information and support during the transition continuum to try and prevent further relationship breakdown. This consideration of the mild stroke experience may help to interpret previous findings related to relationship functioning after mild stroke, especially those that report relationship breakdown (Brey & Wolf, 2015; Carlsson et al., 2004; 2009; Green & King, 2007; 2010; 2011; Gustafsson & Turpin, 2012; Taule & Råheim, 2014; Tellier et al., 2011).

9.3.4 Societal Perceptions

The current societal view of stroke in Australia, which is most likely influenced by the F.A.S.T campaign and misconceptions around stroke being an older person's condition, seems to influence the way that people interpret their experience after a mild stroke. The F.A.S.T. campaign emphasises the observable signs of stroke (Dombrowski et al., 2013), which may heighten expectations of the need for ongoing changes to be able to be outwardly seen. Previous research has found that when societal perceptions emphasise the need for 'disability' to be observable, it can lead people who experience changes that are not observable to also adopt this perspective (Stone, 2005). This can result in them not seeking attention for changes, as they may think they do not warrant attention (Stone, 2005). Furthermore, the variable presentation of mild stroke seems to raise challenges for health professionals, especially in their identification and treatment of the mild stroke event. Consequently, it is important to consider the impact that such understandings have on the individual's experience of mild stroke and encourage people with mild stroke to express changes in their lives.

9.3.5 Support

Services provided to the person with mild stroke contribute to the essence of their experience and may be able to enhance their experiences after acute hospital discharge. Consequently, this is the factor that can be enhanced and changed for the person with mild stroke and their key support person, as it sits outside of them. As identified in Chapter 2.4 - Mild Stroke Services and Chapter 3

– Scoping Review, knowledge surrounding mild stroke specific services is quite limited at present and as knowledge in this area grows, best practice for this population will become clearer. Whilst the current program of research was not able to indicate whether MiStrEnGTH was able to meet the needs of people with mild stroke, it was able to identify that any intervention provided to this population will need to be individualised due to the myriad of ways in which a mild stroke can be experienced. Consequently, a spectrum of services may be needed to choose from for this population, with variability in the level of support required. For instance, some may simply require the provision of education, but others may require ongoing follow-up support in the community.

9.3.6 Essence of Mild Stroke Experience

An individual's mild stroke experience will be different for each person depending on the sum of the influencing factors surrounding it, described above.

9.3.7 Health, Well-being and Engagement

This sits within the 'essence of mild stroke' and can be enhanced by the provision of appropriate services. A person's health, well-being and engagement portrays their ability not only to be free of illness and its impact but also their ability to participate in everyday life to their full potential.

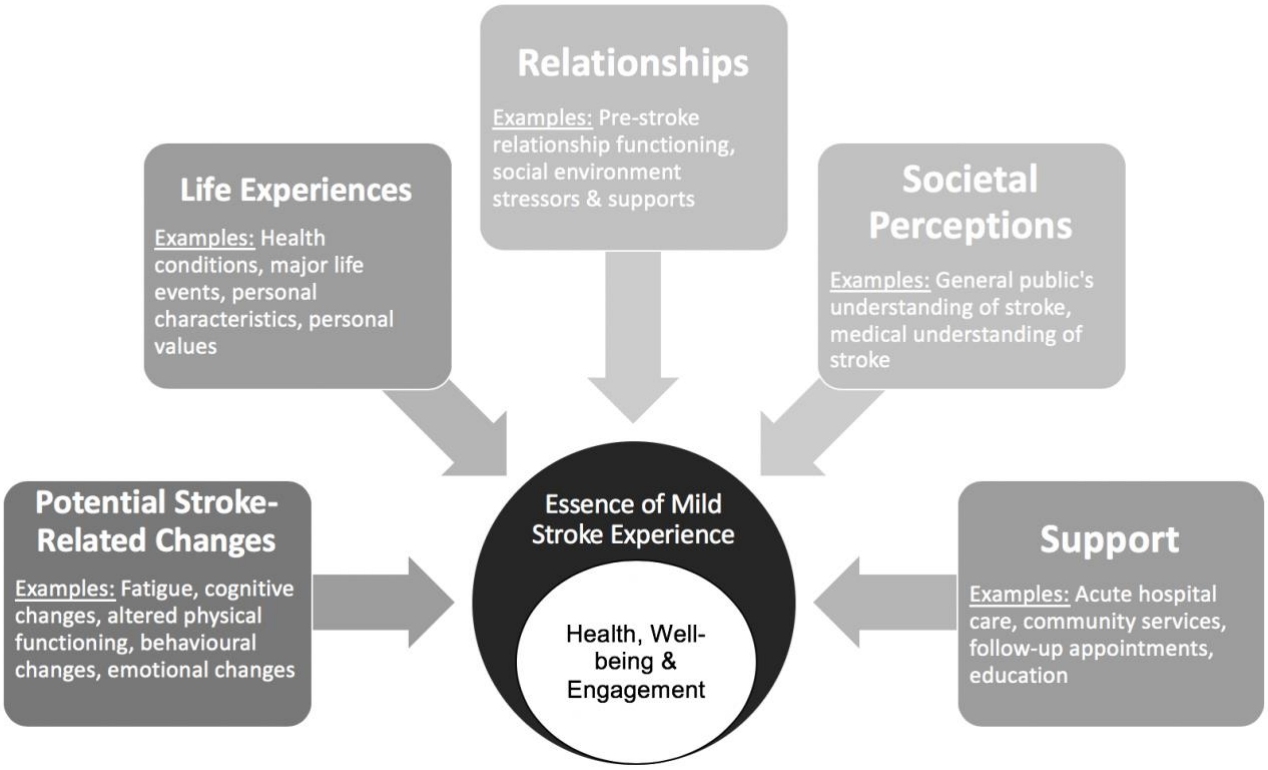

Figure 9.1 Schematic Representation of Findings

9.4 Implications for Health Services & Systems

Findings emphasise that current understandings of stroke within society impact on the identification, understanding and treatment of mild stroke. Consequently, the identification and understanding of mild stroke needs to be improved and it is proposed that a health services and systems approach could be one potential avenue for addressing this. The following discussion will focus on areas, based on Figure 9.1 that can be targeted by health services and systems in order to improve the identification and understanding of mild stroke.

9.4.1 Societal Perceptions

Norrving and colleagues (2018) recently identified that although stroke symptoms and the importance of immediate action have been communicated to the public through campaigns such as F.A.S.T., awareness is still unsatisfactory in the general population. As discussed previously in this chapter, the delay in identifying mild stroke is most likely due to the fact that symptoms often do not align with the face, arm, and speech symptoms outlined in such F.A.S.T. campaigns. Furthermore, emphasising these symptoms may increase the assumption that for someone to experience difficulties after mild stroke, they must be observable. Consequently, further widespread education is required to inform the general public on the more ambiguous symptoms of mild stroke, with emphasis placed on the need to seek timely treatment and support even if the person perceives it as minor. However, in order to have governments invest in such a costly undertaking justification for the economic savings that this will allow will need to be provided and this requires further research.

9.4.2 Support

The findings indicate that health professionals may be experiencing some difficulty in identifying mild strokes as a consequence of ambiguous symptoms. It is acknowledged that enhancing care within the first 24 hours after stroke is vital for reducing the damage to the brain, minimising the impact of stroke, and the risk of further stroke (Wright et al., 2012). Consequently, expedient assessment and management by stroke physicians, optimally in a stroke unit is needed (Wright et al., 2012). As previously discussed, it may be that when people with mild stroke are presenting to emergency departments or general practices their symptoms are not always associated with stroke, impacting on the speed with which they are assessed and treated. Further research in this area is therefore warranted to understand why these issues are occurring, including ways to improve the identification of mild stroke. This research should however be undertaken by health professionals and researchers in the acute stroke field.

Gaps were identified in post-acute care services for people with mild stroke. This finding has also been acknowledged in the general stroke field. For instance, Andrew, Busingye, Lannin, Kilkenny and Cadilhac (2018) identified that only half of the people with stroke who required services received active assistance to organise supports. Similarly, Olaiya and colleagues (2017) reported that 87% of 391 people with stroke in their study had unmet needs in at least one area. The authors went on to comment that services in Australia lack proper coordination to achieve optimal benefits for patients and are not easily accessible or individualised (Olaiya et al., 2017). Consequently, this area requires attention and development.

One area of post-discharge care that was identified as requiring further attention for people with mild stroke was that of emotional support. This has also been reflected in the wider stroke literature where people with stroke have reported a lack of preparation for managing psychological changes following stroke (Andrew et al., 2018). Moreover, in the acquired brain injury field the transitional period has been identified as one where the risk of depression and emotional distress is heightened (Turner, Fleming, Cornwell, Haines & Ownsworth, 2009). Ongoing, regular monitoring of people after mild stroke to identify emotional needs is therefore required (Finch et al., 2017). Programs that target the emotional needs of people with mild stroke may therefore be beneficial and could be explored.

Secondary prevention receives a wealth of attention within the mild stroke and TIA research field and although it is important to address, mild stroke also impacts many other elements of people's lives above and beyond the risk of a secondary stroke. McHutchison and colleagues (2018) from the United Kingdom identified that in a sample of 264 participants, almost half (47%) had impairments in cognitive functioning and a third had impairments in physical functioning. In the same sample, it was observed that 13% of participants experienced a further TIA, minor stroke or myocardial infarction during one to three years follow-up (McHutchison et al., 2018). These findings led the authors to conclude that long-term negative consequences after mild stroke, particularly in regards to cognition are common, noting that these were present in a relatively young population with a high life expectancy. The higher frequency of ongoing impairments in comparison to secondary events therefore suggests that a change of focus may be required for the mild stroke population (McHutchison et al., 2018). As a result, health services and systems may wish to address these ongoing repercussions of mild stroke in order for this population to live well and productively.

Finally, participants identified issues with coordination of services that were consistent with other findings from Australian health services which have identified a lack of organisation of

follow-up appointments for outpatient care and community services for people with stroke (Andrew et al., 2018). For people with mild stroke, this may stem from difficulties with identifying impairments during acute hospitalisation (Finch et al., 2017). This poor coordination of services may also be a result of multiple funding arrangements and providers, lack of service availability and restrictive eligibility criteria that exists in Australia (Andrew et al., 2018). Having effective pathways from hospital discharge to community care is essential, especially as findings demonstrate how people with mild stroke appreciate the presence of a health professional during the transition period. Currently within Australia, the long-term management of people with mild stroke falls on GPs (Kim & Cadilhac, 2017; Norrving et al., 2018). Whilst GPs may be well positioned to implement and coordinate post-stroke services (Finch et al., 2017; Olaiya et al., 2017), people with mild stroke need to present themselves to their local GP which can be a barrier to service access. Additionally, short consultation periods that are often used in GP clinics restrict their ability to address all areas of need post stroke, and therefore attention may be directed towards life sustaining and saving interventions such as secondary prevention. This means that other areas such as return to work, driving, and the key support person's needs go unidentified and therefore not addressed. Consequently, within the context of current health services in Australia, GPs should be given the opportunity to refer on to other stroke specialists such as nurses and allied health professionals to address such issues (Kim & Cadilhac, 2017). One solution to this may be to have one health professional at each general practice assigned to the management of people in the transition phase of acute onset chronic illness, such as those with mild stroke but also people recovering from cardiac events or mild traumatic brain injuries. Overall, what is clear is that better continuity of care is required after discharge so that this population's needs can be identified and adequately addressed (Finch et al., 2017; Kim & Cadilhac, 2017).

9.5 Implications for Clinicians

The findings from this program of research can be incorporated into current practice by health professionals, especially those working in Australia. However, many health professionals report a lack of confidence in interpreting, synthesising and applying research findings, which contributes to delays in the use of research (Laver, Brown, Cordier & Lannin, 2018). Consequently, this next section will aim to present findings that are specifically applicable to clinicians working in the field. Clinicians may be able to utilise and consider all elements of figure 9.1 in an effort to ensure better outcomes for their patients or clients with mild stroke. Elements of figure 9.1 will again be explored below, but with an emphasis on how clinicians may be able to incorporate them into practice.

9.5.1 Essence of Mild Stroke - Assessment

A number of areas to consider when working with people with mild stroke have been highlighted that may determine the impact that the mild stroke has on their experiences after acute hospital care. These considerations ultimately can direct what interventions clinicians decide to provide. Such factors include the person's: stroke-related changes, personal traits, past life and health experiences, relationship functioning prior to the stroke event, stage of life, culture and society in which they live, co-morbidities and current life stressors. The wider stroke literature emphasises that recovery is heterogenous, highly individualised and incorporates an interaction between physical, personal and organisation factors (Hayward, Aitken, Barker & Brauer, 2014; Lannin, 2010). Eriksson, Baum, Wolf and Tabor Connor (2013) further identified the varied nature of community reintegration after mild stroke in their research, where it was observed that participants had a wide range of Stroke Impact Scale scores despite similarities in stroke severity. The consideration of such elements has also been endorsed by the recent Action Plan for Stroke in Europe (Norrving et al., 2018). Within this action plan, it is outlined that a person with stroke's stage of life and home, education and work occupations need to be identified in order to determine their priorities and goals for reintegrating into daily life (Norrving et al., 2018). Figure 9.1 provides a schematic representation that may assist in complying with such an action plan.

The difficulties that people with mild stroke experience are not always easily identifiable during acute intervention periods. Steps towards advancing this field have been taken though, especially in regards to the development of assessment tools that identify cognitive difficulties in this population. For instance, the Complex Task Performance Assessment now has an alternative form allowing for serial administration and evaluation of high-level cognitive deficits in people with mild stroke, whilst mediating for learning effects (Saa et al., 2017). This tool can therefore be utilised by clinicians to screen for more high-level cognitive deficits and may be especially applicable to people working at the time of their mild stroke. Alternatively, it has been suggested that neuropsychological assessments can identify deficits in the mild stroke population and their impact on functioning (Finch et al., 2017). However, many of the issues that this population experiences will only become apparent once they return home and re-engage in their usual daily activities and extend beyond cognitive sequalae. Consequently, the value of real-world experiences and observations in addition to formal assessments must be taken into consideration.

Finally, for people working in hyper-acute and acute areas of stroke care, the ability to diagnose mild stroke was observed to be difficult and requires further attention. It is important to undertake appropriate neuroimaging for people with mild stroke as it plays a vital role in acute

diagnosis and medical management (Norrving et al., 2018; Stinear & Ward, 2013). For people experiencing mild stroke or more ambiguous symptoms this often needs to be in the form of MRI scanning, as CT scans do not always identify their infarcts. Resource limitations are often a barrier to the provision of such assessment however, and as such further cost-analysis and research by acute stroke clinicians would need to be undertaken for this to become a blanket recommendation.

9.5.2 Support

Results emphasised the need for clinicians to prepare the person with mild stroke and their key support person for changes that may be present, especially during the first month at home. This may include screening for risk of emotional changes and directing intervention appropriately (Finch et al., 2017). Furthermore, it could also include discussing with key support persons and people with mild stroke the impact of not being able to engage in all desired occupations during this time. Additionally, clinicians should consider providing information on driving restrictions and alternative transport options (Finch et al., 2017) to reduce the impact on key support persons during the first month at home. Overall, it appears that it is especially important to prepare the person with mild stroke and their key support person for the changes that are particularly apparent in the first month at home, post-acute hospital discharge.

The need for health professionals to monitor people with mild stroke longitudinally was also identified. This includes the screening and provision of information at appropriate times, as needs change and other health conditions take precedence (Norrving et al., 2018). For instance, GPs working with people with mild stroke may need to monitor when they are ready to return to work and ensure they are referred to appropriate services (Norrving et al., 2018; Sinclair, Radforrd, Grant, & Terry, 2014). Moreover, identifying the impact of further conditions and people's engagement in secondary preventative behaviours also needs to be considered (Norrving et al., 2018). Additionally, key support persons' needs should also be monitored including how changes in the person with mild stroke may be impacting on their lives and emotional functioning. Overall, the responsibility of meeting the needs of people with mild stroke in the current Australian healthcare climate is predominantly placed on GPs. Consequently, further attention and funding is needed in this area in order to enable the provision of appropriate services.

In order to give clinicians a more practical application of the above recommendations, two case studies have been provided below. These case studies utilise the schematic representation of findings (Figure 9.1) as a way of clinically reasoning what services to provide. The case studies then allude to potential outcomes for the person with mild stroke dependent on the services they

receive. It must be noted that these cases have been developed by the doctoral candidate and outcomes are hypothetical.

9.5.3 Case Study 1 – Increased No. of Services Needed

Ben is a 36-year-old male who recently presented at his GP with reports of re-occurring headaches and some ongoing tingling in his right hand. The GP referred him to his local hospital for further investigations. A MRI identified an ischaemic left thalamic mild stroke and he was discharged after 2 days in hospital with antihypertensive medication and a Stroke Foundation discharge pack. Ben's GP was sent a discharge report and Ben was informed to see his GP. After a month, Ben presented at his GP and his GP gathered the following information from Ben and his medical file:

- **Stroke-Related Changes:** Increased anger, loss of concentration, difficulty holding objects in his right dominant hand for long periods of time, and fatigue.
- **Relationships**: Ben has a partner of 2 years and they have four children in their care, two of whom are from Ben's previous relationship. After experiencing the mild stroke, Ben has been having arguments with his partner. Most of these arguments have stemmed from his behavioural changes and financial difficulties due to his inability to return to work as a carpenter. He is unable to receive sick leave due to being on a part-time contract.
- **Life Experiences**: Ben has not had any previous major physical health events, however has a history of alcohol abuse. He had a marriage breakdown 5 years ago and experienced depression following this. His children are very important to him and he works hard to provide a good life for them.
- **Societal Perceptions:** Ben is confused about why he experienced a stroke and stated 'but I am not overweight and I am young, I guess it was just a freak accident'. The identification of Ben's stroke was quite quick after hospital admission, however there was a lapse in time between his stroke incident and presentation at hospital.

Ben's GP identified that Ben had a number of potential barriers for community reintegration and referred to the following services:

- Social Work – to address loss of income.
- Psychology – to address changes in emotions and issues occurring in his relationship.
- Occupational Therapy –to address challenges encountered in daily life, including return to work, given residual deficits in cognition, fatigue, and upper limb strength.

Additionally, Ben's GP provided him with information in regards to secondary prevention and stated that he will check how Ben is going with this in a month's time.

One month later, Ben received a reminder on his phone for his follow-up appointment from his GP's clinic which uses electronic reminders. When Ben visited his doctor, he reported that he had been able to obtain income through Centrelink, which the social worker organised for him. Ben stated that his occupational therapist was developing a return to work plan with his employer and had assisted him with rehabilitative and compensative techniques to address his cognitive, fatigue and upper limb issues. Ben stated that his psychologist had been working with him and his partner, and whilst they were still experiencing some issues their relationship had improved. Ben reported that he had been eating somewhat better, but was uncertain about what exercise he could do, and he had been drinking more. His GP discussed appropriate exercises and advised against high levels of alcohol consumption and the risks associated with it. His GP communicated concerns around alcohol consumption with Ben's psychologist with his permission.

Outcome

Ben's GP continued to book in monthly appointments over the proceeding 6 months, which Ben attended. Additionally, Ben saw his psychologist once a month and his occupational therapist until he returned to work. At 6 months post-discharge Ben was working part-time (5-hours per day, 5 days a week) at his previous employer. He returned home in the afternoons to look after the children, while his partner worked in the evenings. Ben and his partner still had some disagreements, but had learnt how to resolve these. His fatigue had resolved, but he still experienced memory issues at times which he addressed through using reminders on his phone. His drinking had reduced due to his continued interaction with his psychologist and increased level of activity and participation. He had started going for a walk to the local park with his children three times a week. Overall, while Ben's life was not exactly as it was before the stroke, he had returned to a life in which he was actively engaged and felt productive.

9.5.4 Case Study 2 – Decreased No. of Services needed

Vera is an 84-year-old women who was living with her daughter and her daughter's family at the time of her mild stroke. Her daughter is a registered nurse and when she noticed her mother's speech slurring one morning, she rushed her straight to hospital, suspecting a stroke. An MRI demonstrated that Vera had had an ischaemic left middle cerebral artery stroke. Vera's stroke team identified that she was experiencing mild difficulties in her speech production and referred her for a speech pathology assessment during her acute hospital stay. The speech pathologist provided Vera with education and exercises and referred her to a community speech pathologist in her local area. Additionally, Vera was prescribed antihypertensive medications and provided with a Stroke

Foundation discharge pack. Vera's GP was notified of her mild stroke, and her daughter booked a follow-up appointment immediately following her discharge.

Vera's GP identified the following information from Vera, his past communications with her and her medical file:

- **Stroke-Related Changes:** Mild speech changes and fatigue.
- **Relationships**: Vera is a widow, her husband passed away from cancer two years prior. After his passing, Vera moved in with her daughter, son-in-law and two teenage grandchildren. She lives in a self-contained granny flat on her daughter's property. Vera has a close relationship with the family, but remains relatively independent. In addition, she has a son and stays with his family every second weekend. Apart from Vera's speech issues and fatigue, her family had not noticed any difference in her behaviour.
- **Life Experience**: Vera has a 'day to day' approach to her life. Vera has no history of mental health issues; however, has type 2 diabetes.
- **Societal Perceptions:** Vera has had two friends recently experience a stroke and stated that 'It is probably one of those things that happens when you get older, but I guess I should start watching my diet a bit more'. The identification and treatment of Vera's stroke was very quick.

Vera's GP discussed with Vera her current diet and simple changes she could make. As her daughter was able to attend the GP appointment, the GP discussed what the family normally ate and how to tailor this for Vera. The GP scheduled an appointment for a month's time and encouraged Vera to continue to see her Speech Pathologist.

Outcome

Vera was discharged from speech pathology at 3 months post hospital discharge with minor ongoing speech changes. Vera's GP was satisfied with the changes that she and her daughter had made to her diet and she had reduced her weight by 2kg. Overall, Vera felt like she had received appropriate support after her discharge and that her life had remained pretty much the same as it was prior to the stroke.

9.6 Implications for Research

Areas for future research have been identified within each study presented as chapters in this thesis. This final discussion aims to bring these areas together and give a comprehensive overview of recommendations for future research in the mild stroke field, drawing upon Figure 9.1 to do so.

9.6.1 Enhancing the Understanding of the Essence of the Mild Stroke Experience

Further research to explore the influence and interplay of contextual factors on the mild stroke experience is warranted. Whilst the current program of research has been able to uncover a number of potential factors to consider, more research is needed in different contexts, including: different countries, socioeconomic statuses, working statuses, people of differing ages, races and genders. Turner and colleagues (2018) from the United Kingdom also emphasised the need for this research, particularly in understanding experiences of current care in different locations. Other researchers in the general stroke field have also enforced this, paying particular attention to outcomes for younger people with stroke (Lannin et al., 2017). Exploring these outcomes from a longitudinal perspective, including the economic implications for future generations would also be helpful to direct services accordingly.

The impact on family members, including children has been proposed as an area needing further research (Turner et al., 2018). Understanding the impact of mild stroke on key support persons, particularly in those who are younger and possibly working and raising children will better allow identification of the best ways to support them in the long-term (Lannin et al., 2012). The results further identify that understanding the dynamics of relationship functioning may also assist with determining the needs of spouses. Overall, key support persons require further attention from researchers in order to ensure their well-being is maintained. Developing this understanding for key support people, in addition to the experiences of people with mild stroke will allow ongoing refinement of the schematic figure presented in this discussion and support the development of supports that best meet their collective needs.

Finally, an unexpected area that was highlighted as needing further research as a consequence of the findings from the current program of research was in relation to travel after mild stroke. It appears that travel, other than that of physical functioning and community mobility, is an area of stroke research that has yet to be explored thoroughly. This may be a consequence of it being seen as a luxury rather than a necessity; however, if people are to live enjoyable, productive lives after stroke, further research in this area is needed.

9.6.2 Support

Understanding why diagnostic difficulties are occurring for people with mild stroke was identified as a continuing research need. UK researchers, Turner and colleagues (2018) also identified this as an issue in their one day priority-setting meeting involving people with mild stroke and TIA, health professionals, stroke charities and stroke researchers. Consequently, it appears that this issue is not

just occurring in Australia and may be one that should be investigated further on an international basis. This area, however should be investigated by researchers and clinicians who specialise in the hyper-acute management of stroke who know the intricacies of the processes in this period.

In regards to follow-up services, participants in this research were not able to explicitly identify the benefits of participating in the MiStrEnGTH program; however, indicated that having a formal support person assisted their feelings of security after mild stroke. This was also reflected by participants being appreciative of the researchers who provided "follow-up". This finding should be taken into consideration during further research as it appeared that the presence of researchers themselves can impact on people's feelings of support which may impact on research findings, as was the case in this study. The optimal way to provide services to people with mild stroke consequently remains unclear, however, further quantitative findings from the RCT within which this research was embedded will help with such interpretation. Support for research in this area has been indicated by a number of authors, who have stated that optimal management in the delivery of healthcare for people with mild stroke still requires further research (Finch et al., 2017; Lannin et al., 2012; Turner et al., 2018). Specific service areas to be addressed include those that cater for people of working age (Lannin et al., 2017), return to work (Sinclair et al., 2014), follow up care and the best setting for it (Turner et al., 2018). Consideration of the impact of the medical model and an impairment-centred approach is needed and the development of future services should incorporate a strengths-based approach for this population. Conclusively, this area of stroke knowledge is still young, and the current program of research has contributed findings that may be able to guide future researchers in addressing this area of need.

9.7 Strengths of the Program of Research

This program of research has a number of strengths that have contributed to the depth of information that it has been able to produce. Firstly, the longitudinal nature of the research conducted is a major strength as it was able to identify issues experienced by people with mild stroke and their key support persons over the critical transition period. Secondly, the use of IPA has allowed for a further level of interpretation and understanding of the mild stroke experience and why issues may be occurring in this population. As outlined in the 'Methods' section of this program of research, IPA allows for a deep exploration of the essence of individual experiences and has been highlighted as an effective method for exploring the lived experiences of individuals undergoing care and experiencing major life experiences (Finlay, 2011; Finlay & Ballinger, 2006; Smith & Osborn, 2008; Smith et al., 2009). Consequently, the current research program has added

an extra layer to the existing qualitative studies that have explored this phenomenon through more descriptive approaches. Furthermore, by concentrating on the experiences of a smaller number of individuals, nuances of the mild stroke experience were able to be revealed. Finally, the utilisation of a second and third researcher in data analyses increased the reliability of the results produced.

9.8 Limitations of the Program of Research

Whilst this thesis contributes new information to the mild stroke knowledge base regarding the experiences of people with mild stroke and their key support persons during the first 6- to 9- months after hospital discharge, it does have some limitations that need to be acknowledged. Each results chapter has identified specific limitations applicable to the individual study, consequently this section will discuss more broadly the research limitations of the thesis in its entirety.

Firstly, due to the small number of participants included within this research, and the fact that it was conducted in only one metropolitan health district in Australia, the ability to generalise information is limited. However, effort has consciously been made to elaborate on the context of the study and the demographic details of participants have been provided in order to increase the ability of readers to transfer findings to their particular context. Transferability however, is limited by a few elements of this study. Firstly, there was only one participant with mild stroke that was female and this limits the representation of the female mild stroke experience and the ability of readers to apply results to their female patients with mild stroke. Likewise, all key support person participants were female and were all approximately the same age, limiting the ability of readers to transfer results to male key support persons and those of differing ages whose experiences may differ. Similarly, all participants included in this thesis were aged over 40 years of age, restricting the transferability of results for adults in their twenties and thirties.

Recruitment was also an issue for this research project. Ethical approval for this research occurred at a latter point in the RCT's participant recruitment, during a time in which project officers were on leave and not back-filled. Consequently, the initial desired numbers for the project were not achieved; however, the final number recruited still aligned with the suggestions by Smith and colleagues (2009) for the design of PhD studies.

It must also be noted that this research was not co-designed with people with mild stroke and their key support persons. This may have resulted in some areas not being investigated that they may have found important. An attempt was made to counteract this issue by giving participants the space to discuss any other matters on their mind at the end of interviews, and the open-ended nature of interviews.

The PhD candidate is also aware that she is an early qualitative researcher and still developing her qualitative skills. Consequently, there were times where questions may have been asked in a slightly leading manner; however, this was taken into consideration during data analyses. Furthermore, whilst the PhD candidate kept a paper trail of her analyses and communications between researchers, she did not use a reflexive journal regularly which may have impacted on the interpretations produced in this program of research.

Finally, at the time of completion of this thesis, results from the RCT were yet to be produced and consequently it is unknown whether findings from this program of research are supported by the quantitative results.

9.9 Conclusion

This program of research aimed to explore the essence of the experience of transitioning to home after acute hospital discharge for people with mild stroke and their key support persons. Furthermore, it also had the goal of exploring this phenomenon under two different models of care. Findings have identified that the transitional experience of people with mild stroke and their key support person is highly dependent on a number of factors that sit alongside the effects of the mild stroke itself. These factors include the person's experience with life and health events, their personal values and beliefs, their previous relationship functioning and societal understandings of mild stroke, inclusive of the understanding held by the health profession. These factors when combined with the effects of the mild stroke itself, result in the essence of the mild stroke experience. This essence then determines what support people with mild stroke may require. If people with mild stroke are provided with the right level of support, it is possible for them to continue to live well and productively.

The findings from this project cannot be undervalued, with recent Australian reports identifying that mild stroke not only contributes substantially to the overall stroke population in Australia, but more and more individuals between the ages of 18 and 64 are contributing to this population (Lannin et al., 2017). Whilst this population reports higher health related quality of life scores than their older counterparts, their scores are lower than the aged matched general population (Lannin et al., 2017). This reflects findings of the current program of research and brings into question the difference between surviving and living after stroke. As the number of mild strokes increase, it is essential that stroke services move past a focus on survival and look instead at assisting a population that continues to experience ongoing implications and enable them to continue to live meaningfully and participate in society for the long term (Hoyle et al., 2012; Wolf et al., 2009; Norrving et al., 2018).

10: Bibliography

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Appendix 1: Scoping Review Inclusion Criteria – Detailed

Concept: Interventions and services offered to people with mild stroke after hospital discharge, to help them to adjust to their "newfound disabilities".

- Interventions and services: relating directly to improving the adaptation of individuals to new found disabilities.
- Needs to be after hospital discharge and provided in the community.
- Preferably self-management related interventions.

Target Population: People with mild (or minor or non-disabling) stroke.

- Some articles will include TIA with people with mild stroke, these will be included.

Health Outcomes of Interest: Psychological and physical health outcomes of specific interventions and services.

Appendix 2: Interview Guide (Studies 1-3)

MiStrEnGTH PhD Project: Participant with Mild Stroke Interview Guide

This interview guide aims to address the following two questions:

- **Primary Research Question:** "How do people with mild stroke experience their transition home from acute hospital care?"
- **Secondary Research Question:** "What are people with mild stroke's perceptions of the MiStrEnGTH (Mild Stroke Enhancing and Guiding Transition Home) program in comparison to standard care?"

Commence interview with introduction of self and thank the participant for agreeing to partake in study. Provide participant with a brief overview of the interview and ask if they have any questions.

Question 1: "Tell me about your experience of returning home after having a stroke."
Within this, the following prompts may be used in order to cover all topic areas. The order of topic areas will be dependent on the flow of conversation.

Home Life/Daily Activities:

- Meaningful occupations, ADL's & Time use.

Leisure:

- Location, time use, and changes in leisure participation.

Employment/Work:

N.B. Will only be explored with individuals who were working prior to stroke.

- Change in roles, productivity, difficulties experiences, & work environment.

Driving:

N.B. Will only be explored with individuals who were driving prior to the stroke.

- Return to driving, information received in regards to driving, confidence & public transport use.

Personal Relationships:

- Changes in friend and family relationships.

Physical & Emotional Health:

- Fatigue, sleep, physical abilities, emotions (e.g. self-esteem), expectations, general outlook on life and perception of self.

Lifestyle Habits:

- Exercise, eating, smoking, medication use, and stroke knowledge.

Question 2: “How has your experience been with health services?”

- Suggested changes, support and services they received.

“Would you like to add anything else?”

Appendix 3: Interview Guide (Studies 1 & 4)

MiStrEnGTH PhD Project: Carer Participant Interview Guide

This interview guide aims to address the following two questions:

- **Primary Research Question:** "How do people with mild stroke experience their transition home from acute hospital care?"
- **Secondary Research Question:** "How do people experience the MiStrEnGTH (Mild Stroke Enhancing and Guiding Transition Home) program in comparison to standard care?"

The purpose of the carer interview is to compare and contrast the findings from the participants with stroke and to identify whether client statements are reflected within the perceptions of others in their lives.

Commence interview with introduction of self and thank the participant for agreeing to partake in study. Provide participant with a brief overview of the interview and ask if they have any questions.

Question 1: "Tell me about how you perceive the stroke effected _____(insert person with mild stroke's name)."

Within this, the following prompts may be used in order to cover all topic areas. The order of topic areas will be dependent on the flow of conversation.

Home Life/Daily Activities:

- Meaningful occupations, ADL's & Time use.

Leisure:

- Location, time use, and changes in leisure participation.

Employment/Work:

N.B. Will only be explored with carers of individuals who were working prior to stroke.

- Change in roles, productivity, difficulties experiences, & work environment.

Driving:

N.B. Will only be explored with carers of individuals who were driving prior to the stroke.

- Return to driving, information received in regards to driving, confidence & public transport use

Physical & Emotional Health:

- Fatigue, sleep, physical abilities, emotions (e.g. self-esteem), expectations, general outlook on life and perception of self.

Lifestyle Habits:

- Exercise, eating, smoking, medication use, and stroke knowledge.

Question 2: "Can you tell me a bit about how _____ having the stroke effected your daily life?"

Home Life/Daily Activities:

- Changes in ADL's & time use

Leisure:

- Changes in leisure participation

Employment/Work:

N.B. Will only be explored with carers who were working prior to mild stroke.

- Change in employment type/hours/work environment.

Driving:

N.B. Will only be explored with carers of individuals who were driving prior to the stroke.

- Change in driving patterns/transport use

Personal Relationships:

- Changes in relationships

Emotional Health:

- Sleeping patterns & emotions (e.g. self-esteem).

Lifestyle Habits:

- Changes to carer's exercise, eating and smoking patterns, as well as stroke knowledge.

Question 3: "How has your experience been with health services?"

- Suggested changes, support and services they received.

"Would you like to add anything else?"

Appendix 4: Participant Information and Consent Forms (Participant with Stroke & Key Support Person) – Royal Brisbane and Women's Hospital

Participant Information Sheet

Patient group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	**Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)**
Name of Researchers:	**Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson**
Sponsor Details:	**HP Research Major Grant Scheme**

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in the research project: **"Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)".** You have been invited to participate as you have had a mild stroke and are going home. The project aims to compare our usual care processes for managing your recovery to a new allied health-led model of care.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what you would do in the study if you agree to participate. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project
• Consent to the tests and research that are described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of the study is to compare two models of care for supporting recovery after mild stroke. The focus is on people who have had a mild stroke and go straight home from acute hospital care. The first model is the current model of care (described in section 3 of this form) at the Royal Brisbane and Women's Hospital. The second model is a new allied health-led approach. We want to know how each model of care may impact your quality of life, general mood, participation in daily activities and community life. We also want to know how the lives of your family members or carers may be affected, including their mood or other aspects of their life. This project will allow us to see which model of care best supports survivors of mild stroke and their family after hospital discharge.

Issues that may impact over time on survivors of mild stroke and their family members include reduced quality of life and depression. The time when you first go home after your stroke is an important phase of your recovery. You will look to return to all parts of your life at home and in the community. Many survivors of *mild stroke* have reported being independent in everyday activities at home. They often report though changes in their emotions and quality of life, as well as a sense of not being prepared either mentally or physically to return to their lives in the community. This research intends to compare two models of care to see how well each one addresses the needs of survivors of mild stroke, and to inform our practice in the area of stroke care.

This research is funded by the Health Practitioner Research Major Grant Scheme.

3. What does participation in this research involve?

Participants recruited to the study will be survivors of mild stroke. You would also be asked to identify a close family member or friend who will support you in the first six-months after

your stroke who could be involved. If you join the study you will be allocated randomly to one of two treatment groups. One group will receive current usual care, while the second group will receive the new model of care. All participants will have had a mild stroke and have been admitted to an acute ward at the Royal Brisbane and Women's Hospital.

If you agree to participate in the study, you will need to sign the consent form. A member of the research team will obtain information about you (e.g. age, employment status, type of stroke) from either the hospital records or yourself. You will be asked to identify a person who is going to be your primary support person in the first 6-months after your stroke. We will invite them (with your permission) to participate in the study too. The first step of the project will see you complete a number of questionnaires at the time of your discharge from hospital. The questionnaires will look at topics such as your quality of life, mood, participation in daily activities and community life. You will also be asked to rate your satisfaction with the stroke services you have received. At this time you will also complete tasks that assess your thinking skills (known as cognition) which can be affected in some people after mild stroke. The total time to complete the assessments would be around 1¼ hour. Assessments may be conducted at the Royal Brisbane and Women's Hospital prior to you leaving hospital for the initial session or in your home if required. The questionnaires will be completed again at 1-, 3- and 6-months after your stroke. At these times a member of the research team will come to your home to assist with completing the questionnaires. If you happen to be attending a hospital clinic appointment at these times the session could be done at the hospital. These sessions will be organised at a time convenient to you.

As well as the questionnaires at 1-, 3- and 6- months, a small number of people (up to 16) may also be asked to take part in interviews. The number of interviews that you may be asked to take part in would vary from 1 to 4 and would occur at 1-, 3-, 6- and/or 9- months. Topics covered in these interviews will include: work, leisure, community and home-life activities, mood, driving, personal relationships and satisfaction with care received. These interviews should last between 1 and 2 hours and will occur within your home or at an agreed location. All interviews will be conducted at a time that is convenient to you and not on the same day as the questionnaires. You will be given the choice to participate in just the questionnaires, or in both the questionnaires and interviews.

After the initial assessment you will receive either current usual care or the new allied health-led service. If you are allocated to the usual care group, services will be provided by your

treating health team. This group will be referred to as to the “standard care” group. Usual care for mild stroke patients includes some or all of the following:

1. education related to stroke by a Stroke Nurse or Allied Health Professional;
2. referral to see local General Practitioner (GP), with a hospital report sent directly to your nominated GP to tell them about your stroke and recommendations for care;
3. follow-up appointment at the Royal Brisbane and Women’s Hospital outpatient clinic between 1 and 3 months post-hospital discharge;
4. provision of information for local peer stroke support groups; and
5. referral to or provision of information on local community-based programs and services (e.g. home help, meals on wheels).

If you are allocated to the allied health-led service the group will be known as the “MiStrEnGTH” group. This model of care is being trialled in this research. You will receive the same services as ‘standard care” plus up to 5 phone calls over the first 6-months after your stroke. These phone calls will checking how you and your family member are managing following your stroke and return home. You will receive phone calls at the following times:

- 1-week after discharge from hospital
- 4-weeks after discharge from hospital
- 8-weeks discharge from hospital, and
- then two more phone calls can be scheduled between 2- and 6-months after your stroke. The timing of these phone calls will be decided you and the research therapist.

4. What are the possible risks and side effects of taking part?

There are no to minimal risks or side effects to you from taking part in this study. For all participants with stroke, basic information will be collected. The information collected will include your age, gender, type of stroke, and site of the stroke. The assessment tasks you will complete during various stages of the study are described in the table below. Tasks will assess your quality of life, mood, thinking skills, daily activities undertaken, and participation in the community. These tasks should not cause significant discomfort. You may be inconvenienced in terms of the time commitment required to participate in the study; however every effort will be made to schedule sessions at times that are convenient to you. If necessary, the assessments can be completed over a number of sessions.

The risk of harm to you is considered extremely low. Some of the questions asked may result in you feeling particular emotions. You may feel upset, angry or other emotions during the

assessment and/or interview, particularly in relation to your stroke and how it has impacted your life. These responses may be part of the adjustment process after your stroke, or a direct impact of your stroke. The research therapist will talk with you about these emotions and provide strategies or ideas to manage these emotions with a view to reducing their impact on your recovery. For all participants (individuals with stroke and their family members), the research team will seek to manage this risk. This may involve them assisting you to connect with appropriate supports (e.g. your GP, or phone based services such as Lifeline).

Assessment Tasks – Total time to complete 1¼ hours			
Participant with Stroke	**Task Description**	**Time to complete**	**Assessment points**
Assessment of Quality of Life - 4D (AQoL-6D)	You will complete a 20 item questionnaire that asks questions about independent living, mental health, coping, relationships, pain, and senses.	5 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Depression Anxiety Stress Scale – 21 (DASS-21)	The DASS-21 is a 21-item questionnaire that requires you to respond to statements relating to symptoms of depression, anxiety and stress.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Reintegration to Normal Living Index (RNLI)	You will be asked 11 questions that ask about the degree you have returned to life activities (e.g. recreation, movement in the community, and interaction in family or other relationships).	10 minutes.	1 month, 3 months, & 6 months post discharge
Fatigue Scale for Motor and Cognitive Functions (FSMC)	The questionnaire has 20-items that ask you about symptoms of mental and physical fatigue.	<10 minutes.	Discharge, 1 month, 3 months, & 6 months post discharge
Confidence After Stroke Measure(CASM)	The CASM is a 27-item questionnaire which asks you to answer questions about your self-confidence, positive attitude, and social confidence.	10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Service Satisfaction VAS	You will be asked to rate your satisfaction with the care you've received related to your stroke. On a line you will be asked to indicate you level of satisfaction where 0=worst possible care, and 10=best possible care.	1-2 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Trail Making Test Part A & B	This is a pencil and paper test where you will be required to	<10 minutes	Discharge

	connect letters and / or numbers according to instructions given by the assessor.		
Snellgrove Maze Test	This is a pencil and paper test where you will be required to solve a maze following a set of instructions.	About 5 minutes	Discharge
Letter-Number Sequencing Task	The LNS task requires you to repeat back to the assessor a series of letters and numbers they have recited. There are some rules that you will need to follow to complete this task..	<10 minutes	Discharge
Controlled Oral Word Association Test	The assessor will ask you name as many words as you can that start with a particular letter, or from a particular category (e.g. clothing).	About 5 minutes.	Discharge
Brief Assessment of Prospective Memory	This 16-item questionnaire asks you to answer questions about situations where you have may forgotten to do things, it is looking at your ability to remember to do something in the future.	<10 minutes.	1 month, 3 months, & 6 months post discharge

5. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with your hospital.

6. What are the possible benefits of taking part?

We cannot promise that you will receive any benefits from this research above that gained from usual clinical practice. Through the project your quality life, general mood and well-being, and participation in life will be monitored. Should you experience changes to your mood or well-being the research therapist will provide advice on accessing support for these problems. If the phone calls received by the MiStrEnGTH group are found to be beneficial above “standard care”, participants in the standard care group will receive a phone call

consultation based on the MiStrEnGTH program at the end of the study. Your involvement in the study will also help us better understand how best to provide stroke services for people living in Queensland and beyond.

7. What are the possible risks and disadvantages of taking part?

There are no foreseeable risks and disadvantages of taking part in this project. The low risk of experiencing negative feelings, such as sadness, when discussing your stroke and any changes you may have experienced after it should be considered.

8. What if I withdraw from this research project?

If you do withdraw your consent during the research project, the research staff will not collect additional personal information from you. The personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

9. Could this research project be stopped unexpectedly?

It is not anticipated that this research project will be stopped unexpectedly.

10. What happens when the research project ends?

At the end of the study the information collected will be analysed and written up for presentation in the scientific community. This may be through peer-reviewed scientific publications or at scientific conferences. If participants would like to receive a written summary of the results of the study they can request this of the research team. Results of the completed study should be available by late 2018.

If you wish to have access to your personal results from any of the tasks, you may contact the investigator named below. You will also be directed to any publications arising from this study.

Part 2 How is the research project being conducted?

11. What will happen to information about the participant?

By signing the consent form you consent to research staff collecting and using personal information about you for the research project. Your privacy and confidentiality will be

maintained at all times during this project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. You will be assigned a study number (e.g. SS001). All relevant data collected about you will be labelled with this number and not your name. Information will be stored safely and securely in a locked filing cabinet in the Allied Health Research Collaborative, The Prince Charles Hospital and in a locked filing cabinet in the School of Health and Rehabilitation Sciences Higher Research Degree Room, The University of Queensland. Information regarding your medical history will only be used by those researchers working on the study. The results of all tests will not be published in a way that could reveal your identity. If you wish to have access to your personal results from any of the tasks you may contact the investigator named below.

All data will be stored for 7 years after completion of the study, except for audio recordings made during the study. The audio recordings will be written out in full and stored in paper format for 7 years. Audio recordings will be erased once the analysis is complete.

12. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible. You will be assisted with arranging appropriate medical treatment. All medical treatment required to treat the injury or complication will be free of charge as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted by the Allied Health Research Collaborative and Stroke Services within Metro North Hospital and Health Service. The project is funded by the Health Practitioner Research Major Grant Scheme. Participation in this research is voluntary and you will receive no payments associated with your participation in the project.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of The Royal Brisbane and Women's Hospital, Griffith University, The University of Queensland, and Australian Catholic University. This

project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you have any queries regarding the nature of this research or the procedure, please feel free to contact the research contact person:

Name	**Dr Petrea Cornwell**
Position	**Principal Research Fellow, Allied Health Research Collaborative**
Telephone	**(07) 3139 6112**
Email	petrea.cornwell@health.qld.gov.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	**Jacqueline Robinson**
Position	**Research Governance Officer**
Telephone	**(07) 3646 8579**
Email	rbwh_rgo@health.qld.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the Royal Brisbane and Women's Hospital Human Research Ethics Committee on (07) 3646 5490 who will forward their concerns to the Chair, Human Research Ethics Committee.

Participant Consent Form

Patient Group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

I agree to participate in the above named project and in so doing acknowledge that:

- I have been informed as to the nature and extent of any risk to my health or well-being.
- I am aware that, although the project is directed to the expansion of medical knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to me.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that my GP may be informed that I am taking part in the project.
- I understand that, in respect of any information (which may consist of records outside of this hospital) including audiovisual records obtained during the course of the project; confidentiality will be maintained to the same extent as for my Hospital medical records. In the event of any results of the project being published, I will not be identified in any way.
- I agree that, if necessary, my medical records (in respect of my involvement in this project) may be inspected by a Research Assessor. This assessor may be external to but approved by the Hospital, provided that the Assessor does not identify me or my hospital's medical records in any way to a third party.

☐ I consent to being approached to participate in interviews, in addition to the assessments. I do, however, understand that not every participant will be approached to participate in the additional interview.

Patient's name: .....Signature: ..... **Date:_ _ / _ _ _ / _ _ _ _**
DD / MMM / YYYY

Name of Investigator: .....Signature: ..... **Date:_ _ / _ _ _ / _ _ _ _**

DD / MMM / YYYY

Withdrawal of Participation

Patient group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

- I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Brisbane and Women's Hospital, Metro North Hospital and Health Service, Griffith University, the University of Queensland, or the Australian Catholic University.

Participant's name (please print): .....

(Signature)..... **Date: _ _ / _ _ _ / _ _ _ _**
DD / MMM /
YYYY

This Withdrawal of Participation should be forwarded to:

Dr. Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital
627 Rode Rd, Chermside
Queensland, Australia 4032

Participant Information Sheet

Carer group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in this research project: **"Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)".** You have been identified by your family member who has had a mild stroke and is going home as their primary support person, and therefore, you are invited to participate in this research project. The project aims to compare our usual care processes for managing the recovery of individuals with mild stroke to a new allied health-led model of care.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what would be involved should you agree to participate. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You and your family member will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project

• Consent to the tests and research that are described

• Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of the study is to compare two models of care for supporting recovery after mild stroke. The first model is the current model of care (described in section 3 of this form) at the Royal Brisbane and Women's Hospital. The second model is a new allied health-led approach. We want to know how each model of care may impact on people with mild stroke. We are interested in their quality of life, general mood, participation in daily activities and community life. We are also interested in knowing how your life may be impacted, including your mood or other aspects of your life. This project will allow us to see which model of care best supports survivors of mild stroke and their family after hospital discharge.

Issues that may impact over time on survivors of mild stroke and their family members include reduced quality of life and depression. The time when a stroke survivor first returns home is an important phase of recovery. Stroke survivors will look to return to all parts of their life in their home and community. Many survivors of *mild stroke* have reported being independent in everyday activities of home. They often report though changes in their emotions and quality of life, as well as a sense of not being prepared mentally or physically to return to their lives in the community. This research intends to compare two model of care to see how well each addresses the needs of survivors of mild stroke and their family, and to inform clinical practice in the area of stroke care.

This research is funded by the Health Practitioner Research Major Grant Scheme.

3. What does participation in this research involve?

Two types of participants will be recruited to the study. The first group is made up of survivors of mild stroke. The second group consists of a close family member or friend who will support them in the first six-months after their stroke. This is the group you would be recruited to in the study. As the identified main carer or support person of a stroke survivor who is participating in the study, we would like to invite you to participate in the study. Your involvement would

involve you completing assessments regarding your mood, and how the “carer” role has affected your life (if at all). We will also ask you to rate your satisfaction with stroke services provided to the person with stroke and yourself. Participants with stroke will be allocated randomly to one of two treatment groups, and you as their carers will be allocated to the same group. One group will receive current usual care, while the second group will receive the new model of care. All participants with stroke will have had a mild stroke and have been admitted to an acute ward at the Royal Brisbane and Women’s Hospital.

If you agree to participate in the study, you will need to sign the consent form. A member of the research team will ask you some questions about yourself (e.g. age, relationship to stroke survivor, employment status). The first step of the project will see you complete a number of questionnaires at the time of the stroke survivors discharge from hospital. The questionnaires will look at topics such as your quality of life, mood, and feelings of carer strain. You will also be asked to rate your satisfaction with the stroke services received. The total time to complete the assessments would be around ½ hour. Assessments may be conducted at the Royal Brisbane and Women’s Hospital prior to the person with stroke leaving hospital for the initial session or in your home if required. The questionnaires will be completed again at 1-, 3- and 6- months after hospital discharge. At these times a member of the research team will come to your home to assist with completing the questionnaires. If you happen to be attending a hospital clinic appointment at these times the session could be done at the hospital. These sessions will be organised at a time convenient to you.

In addition, you may be asked to participate in an interview at 9- months after hospital discharge. This interview will discuss your relationship with the stroke survivor, changes in your home environment that may have happened after the stroke, and satisfaction with care. This interview will be conducted on a separate day to the questionnaires, at a time that is convenient to you. The interview will take place at your home or at a mutually agreed upon location. You will be given the choice to participate in the interview and the questionnaire, or just the questionnaire.

After the initial assessment you and the individual with stroke will receive either current usual care or the new allied health-led service. If you are allocated to the usual care group, services will be provided by the treating health team. This group will be referred to as the “standard care” group. Usual care for mild stroke patients and yourself includes some or all of the following:

1. education related to stroke by a Stroke Nurse or Allied Health Professional;
2. referral to see local General Practitioner (GP), with a hospital report sent directly to your nominated GP to tell them about your stroke and recommendations for care;
3. follow-up appointment at the Royal Brisbane and Women's Hospital outpatient clinic between 1 and 3 months post-hospital discharge;
4. provision of information for local peer stroke support groups; and
5. referral to or provision of information on local community-based programs and services (e.g. home help, meals on wheels).

If you are allocated to the allied health-led service group be referred to as the "MiStrEnGTH" group. This new model of care is being trialled in this research. You will receive the same services as "standard care" plus up to 5 phone calls over the first 6-months after the stroke survivors' hospital discharge. These phone calls will be checking how the person with stroke and yourself are both managing following their stroke and return home.

You will receive phone calls at the following times:

- 1-week after discharge from hospital
- 4-weeks after discharge from hospital
- 8-weeks discharge from hospital, and
- then two more phone calls can be scheduled between 2- and 6-months after your stroke. The timing of these phone calls will be decided you and the research therapist.

4. What are the possible risks and side effects of taking part?

There are no to minimal risks or side effects from taking part in this study. For all carers of stroke survivors, basis information will be collected from you including age, gender, education level and relationship to participant with stroke. The assessment tasks you will be required to complete during various stages of the study are described in the table below. The tasks are designed to assess the quality of life, client mood, carer strain. They should not cause significant discomfort.

You may be inconvenienced in terms of the time commitment required to participate in the study; however every effort will be made to schedule sessions at times that are convenient to you. If necessary, the assessments can be completed over a number of sessions.

The risk of harm to you is considered extremely low. Some of the questions asked may result in you feeling particular emotions. You may feel upset, angry or other emotions during the

assessment and/or interview relating to how stroke has impacted the life of your family member/friend and you. Such responses for you are likely part of an adjustment process to supporting someone with stroke. For stroke survivor such feelings may be due to an adjustment process, or a direct impact of the stroke. The research therapist will talk with you about these emotions and provide strategies or ideas to manage these emotions with a view to reducing their impact on you. For all participants (individuals with stroke and you as the carer), the research team will seek to manage this risk. This may involve them assisting you to connect with appropriate supports (e.g. your GP, or phone based services such as Lifeline).

Carer Participant assessment Tasks – Total time to complete ½ hours			
Assessment of Quality of Life - 4D (AQoL-4D)	You will complete a 20 item questionnaire that asks questions about independent living, mental health, coping, relationships, pain, and senses.	5 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Depression Anxiety Stress Scale – 21 (DASS-21)	The DASS-21 is a 21-item questionnaire that requires you to respond to statements relating to symptoms of depression, anxiety and stress.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Carer Strain Index (CSI)	The CSI is a 13-item questionnaire that asks questions about the impact of taking on a carer or support role. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Service Satisfaction VAS	You will be asked to rate your satisfaction with the care you and your family member have received in relation to their stroke. On a line you will be asked to indicate you level of satisfaction where 0=worst possible care, and 10=best possible care.	1-2 minutes	Discharge, 1 month, 3 months, & 6 months post discharge

5. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your

routine treatment or that of the participant with stroke, your relationship or that of the participant with stroke with those treating team or hospital.

6. What are the possible benefits of taking part?

We cannot promise that you or the participant with stroke will receive any benefits from this research above that which would be gained from usual clinical practice. Through the project your quality life, general mood and well-being, and feelings of carer strain will be monitored. Should you experience changes to your mood or well-being the research therapist will provide advice in regards on accessing support for these problems. If the phone calls received by the MiStrEnGTH group are found to be beneficial above 'standard care", participants in the standard care group will receive a phone call consultation based on the MiStrEnGTH program at the end of the study. Your involvement in the study will also help us to better understand how best to provide stroke services for people living in Queensland and beyond.

7. What are the possible risks and disadvantages of taking part?

There are no foreseeable risks and disadvantages of taking part in this project. The low risk of experiencing negative feelings, such as sadness, when discussing the survivor's stroke and any changes you may have experienced after it should be considered.

8. What if I withdraw from this research project?

If you do withdraw your consent during the research project, the research staff will not collect additional personal information from you. The personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

9. Could this research project be stopped unexpectedly?

It is not anticipated that this research project will be stopped unexpectedly.

10. What happens when the research project ends?

At the end of the study the information collected will be analysed and written up for presentation in the scientific community. This may be through peer-reviewed scientific publications or at scientific conferences. If participants would like to receive a written summary of the results of the study as a whole they can request this of the research team. Results of the completed study should be available by late 2018.

If you wish to have access to your personal results from any of the tasks, you may contact the investigator indicated below. You will also be directed to any publications arising from this study.

Part 2 How is the research project being conducted?

11. What will happen to information about the participant?

By signing the consent form you consent to research staff collecting and using personal information about you for the research project. Your privacy and confidentiality will be maintained at all times during this project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. You will be assigned a study number (e.g. SS001) and all relevant data collected about you will be labelled with this number and not your name. Information will be stored safely and securely in a locked filing cabinet in the Allied Health Research Collaborative, The Prince Charles Hospital and in a locked filing cabinet in the School of Health and Rehabilitation Research Higher Degree Room, The University of Queensland. The results of all tests will not be published in a way that could reveal your identity. If you wish to have access to your personal results from any of the tasks you may contact the investigator indicated below.

All data will be stored for 7 years after completion of the study, except for audio recordings made during the study. The audio recordings will be written out in full and stored in paper format for 7 years, but the audio recordings will be erased once the analysis is complete.

12. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible. You will be assisted with arranging appropriate medical treatment. All medical treatment required to treat the injury or complication will be free of charge as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted by the Allied Health Research Collaborative and Stroke Services within Metro North Hospital and Health Service. The project is funded by the Health Practitioner Research Major Grant Scheme. Participation in this research is voluntary and you will receive no payments associated with your participation in the project.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Royal Brisbane and Women's Hospital, Griffith University, The University of Queensland, and Australian Catholic University. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you have any queries regarding the nature of this research or the procedure, please feel free to contact the research contact person:

Name	**Dr Petrea Cornwell**
Position	**Principle Research Fellow, Allied Health Research Collaborative**
Telephone	**(07) 3139 6112**
Email	petrea.cornwell@health.qld.gov.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	**Jacqueline Robinson**
Position	**Research Governance Officer**
Telephone	**(07) 3646 8579**
Email	rbwh_rgo@health.qld.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the Royal Brisbane and Women's Hospital, Human Research and Ethics Committee on (07) 3646 5490 who will forward their concerns to the Chair, Human Research Ethics Committee.

Participant Consent Form

Carer Group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

I agree to participate in the above named project and in so doing acknowledge that:

- I have been informed as to the nature and extent of any risk to my health or well-being.
- I am aware that, although the project is directed to the expansion of medical knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to me.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that my GP may be informed that I am taking part in the project.
- I understand that, in respect of any information (which may consist of records outside of this hospital) including audiovisual records obtained during the course of the project; confidentiality will be maintained to the same extent as for my Hospital medical records. In the event of any results of the project being published, I will not be identified in any way.
- I agree that, if necessary, my medical records (in respect of my involvement in this project) may be inspected by a Research Assessor. This assessor may be external to but approved by the Hospital, provided that the Assessor does not identify me or my hospital's medical records in any way to a third party.

☐ I consent to being approached to participate in interviews, as well as assessments. I do, however, understand that not every carer will be approached to participate in the additional interview.

Patient's name: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Name of Investigator: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Withdrawal of Participation

Carer group – Royal Brisbane and Women's Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

- I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Brisbane and Women's Hospital, Metro North Hospital and Health Service, Griffith University, the University of Queensland, or the Australian Catholic University.

Participant's name (please print): .....

(Signature)..... **Date: _ _ / _ _ _ / _ _ _ _**
DD / MMM /

YYYY

This Withdrawal of Participation should be forwarded to:

Dr. Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital
627 Rode Rd, Chermside
Queensland, Australia 4032

Appendix 5: Participant Information and Consent Forms (Participant with Stroke & Carer) – The Prince Charles Hospital

Participant Information Sheet

Patient group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in the research project: **"Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)".** You have been invited to participate as you have had a mild stroke and are going home. The project aims to compare our usual care processes for managing your recovery to a new allied health-led model of care.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what you would do in the study if you agree to participate. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project

• Consent to the tests and research that are described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of the study is to compare two models of care for supporting recovery after mild stroke. The focus is on people who have had a mild stroke and go straight home from acute hospital care. The first model is the current model of care (described in section 3 of this form) at The Prince Charles Hospital. The second model is a new allied health-led approach. We want to know how each model of care may impact your quality of life, general mood, participation in daily activities and community life. We also want to know how the lives of your family members or carers may be affected, including their mood or other aspects of their life. This project will allow us to see which model of care best supports survivors of mild stroke and their family after hospital discharge.

Issues that may impact over time on survivors of mild stroke and their family members include reduced quality of life and depression. The time when you first go home after your stroke is an important phase of your recovery. You will look to return to all parts of your life at home and in the community. Many survivors of *mild stroke* have reported being independent in everyday activities at home. They often report though changes in their emotions and quality of life, as well as a sense of not being prepared either mentally or physically to return to their lives in the community. This research intends to compare two models of care to see how well each one addresses the needs of survivors of mild stroke, and to inform our practice in the area of stroke care.

This research is funded by the Health Practitioner Research Major Grant Scheme.

3. What does participation in this research involve?

Participants recruited to the study will be survivors of mild stroke. You would also be asked to identify a close family member or friend who will support you in the first six-months after your stroke who could be involved. If you join the study you will be allocated randomly to

one of two treatment groups. One group will receive current usual care, while the second group will receive the new model of care. All participants will have had a mild stroke and have been admitted to an acute ward at The Prince Charles Hospital.

If you agree to participate in the study, you will need to sign the consent form. A member of the research team will obtain information about you (e.g. age, employment status, type of stroke) from either the hospital records or yourself. You will be asked to identify a person who is going to be your primary support person in the first 6-months after your stroke. We will invite them (with your permission) to participate in the study too. The first step of the project will see you complete a number of questionnaires at the time of your discharge from hospital. The questionnaires will look at topics such as your quality of life, mood, participation in daily activities and community life. You will also be asked to rate your satisfaction with the stroke services you have received. At this time you will also complete tasks that assess your thinking skills (known as cognition) which can be affected in some people after mild stroke. The total time to complete the assessments would be around 1¼ hour. Assessments may be conducted at The Prince Charles Hospital prior to you leaving hospital for the initial session or in your home if required. The questionnaires will be completed again at 1-, 3- and 6-months after your stroke. At these times a member of the research team will come to your home to assist with completing the questionnaires. If you happen to be attending a hospital clinic appointment at these times the session could be done at the hospital. These sessions will be organised at a time convenient to you.

As well as the questionnaires at 1-, 3- and 6- months, a small number of people (up to 16) may also be asked to take part in interviews. The number of interviews that you may be asked to take part in would vary from 1 to 4 and would occur at 1-, 3-, 6- and/or 9- months. Topics covered in these interviews will include: work, leisure, community and home-life activities, mood, driving, personal relationships and satisfaction with care received. These interviews should last between 1 and 2 hours and will occur within your home or at an agreed location. All interviews will be conducted at a time that is convenient to you and not on the same day as the questionnaires. You will be given the choice to participate in just the questionnaires, or in both the questionnaires and interviews.

After the initial assessment you will receive either current usual care or the new allied health-led service. If you are allocated to the usual care group, services will be provided by your

treating health team. This group will be referred to as to the “standard care” group. Usual care for mild stroke patients includes some or all of the following:

1. education related to stroke by a Stroke Nurse or Allied Health Professional
2. referral to see local General Practitioner (GP), with a hospital report sent directly to your nominated GP to tell them about your stroke and recommendations for care;
3. follow-up appointment at The Prince Charles Hospital outpatient clinic between 1 and 3 months post-hospital discharge;
4. provision of information for local peer stroke support groups; and
5. referral to or provision of information on local community-based programs and services (e.g. home help, meals on wheels).

If you are allocated to the allied health-led service the group will be known as the “MiStrEnGTH” group. This model of care is being trialled in this research. You will receive the same services as ‘standard care” plus up to 5 phone calls over the first 6-months after your stroke. These phone calls will checking how you and your family member are managing following your stroke and return home. You will receive phone calls at the following times:

- 1-week after discharge from hospital
- 4-weeks after discharge from hospital
- 8-weeks discharge from hospital, and
- then two more phone calls can be scheduled between 2- and 6-months after your stroke. The timing of these phone calls will be decided you and the research therapist.

4. What are the possible risks and side effects of taking part?

There are no to minimal risks or side effects to you from taking part in this study. For all participants with stroke, basic information will be collected. The information collected will include your age, gender, type of stroke, and site of the stroke. The assessment tasks you will complete during various stages of the study are described in the table below. Tasks will assess your quality of life, mood, thinking skills, daily activities undertaken, and participation in the community. These tasks should not cause significant discomfort. You may be inconvenienced in terms of the time commitment required to participate in the study; however every effort will be made to schedule sessions at times that are convenient to you. If necessary, the assessments can be completed over a number of sessions.

The risk of harm to you is considered extremely low. Some of the questions asked may result in you feeling particular emotions. You may feel upset, angry or other emotions during the

assessment, and/or interview, particularly in relation to your stroke and how it has impacted your life. These responses may be part of the adjustment process after your stroke, or a direct impact of your stroke. The research therapist will talk with you about these emotions and provide strategies or ideas to manage these emotions with a view to reducing their impact on your recovery. For all participants (individuals with stroke and their family members), the research team will seek to manage this risk. This may involve them assisting you to connect with appropriate supports (e.g. your GP, or phone based services such as Lifeline).

Assessment Tasks – Total time to complete 1¼ hours			
Participant with Stroke	**Task Description**	**Time to complete**	**Assessment points**
Assessment of Quality of Life - 4D (AQoL-6D)	You will complete a 20 item questionnaire that asks questions about independent living, mental health, coping, relationships, pain, and senses.	5 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Depression Anxiety Stress Scale – 21 (DASS-21)	The DASS-21 is a 21-item questionnaire that requires you to respond to statements relating to symptoms of depression, anxiety and stress.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Reintegration to Normal Living Index (RNLI)	You will be asked 11 questions that ask about the degree you have returned to life activities (e.g. recreation, movement in the community, and interaction in family or other relationships).	10 minutes.	1 month, 3 months, & 6 months post discharge
Fatigue Scale for Motor and Cognitive Functions (FSMC)	The questionnaire has 20-items that ask you about symptoms of mental and physical fatigue.	<10 minutes.	Discharge, 1 month, 3 months, & 6 months post discharge
Confidence After Stroke Measure(CASM)	The CASM is a 27-item questionnaire which asks you to answer questions about your self-confidence, positive attitude, and social confidence.	10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Service Satisfaction VAS	You will be asked to rate your satisfaction with the care you've received related to your stroke. On a line you will be asked to indicate you level of satisfaction where 0=worst possible care, and 10=best possible care.	1-2 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Trail Making Test Part A & B	This is a pencil and paper test where you will be required to connect letters	<10 minutes	Discharge

	and / or numbers according to instructions given by the assessor.		
Snellgrove Maze Test	This is a pencil and paper test where you will be required to solve a maze following a set of instructions.	About 5 minutes	Discharge
Letter-Number Sequencing Task	The LNS task requires you to repeat back to the assessor a series of letters and numbers they have recited. There are some rules that you will need to follow to complete this task..	<10 minutes	Discharge
Controlled Oral Word Association Test	The assessor will ask you name as many words as you can that start with a particular letter, or from a particular category (e.g. clothing).	About 5 minutes.	Discharge
Brief Assessment of Prospective Memory	This 16-item questionnaire asks you to answer questions about situations where you have may forgotten to do things, it is looking at your ability to remember to do something in the future.	<10 minutes.	1 month, 3 months, & 6 months post discharge

5. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with your hospital.

6. What are the possible benefits of taking part?

We cannot promise that you will receive any benefits from this research above that gained from usual clinical practice. Through the project your quality life, general mood and well-being, and participation in life will be monitored. Should you experience changes to your mood or well-being the research therapist will provide advice on accessing support for these problems. If the phone calls received by the MiStrEnGTH group are found to be beneficial above ‘standard care”, participants in the standard care group will receive a phone call

consultation based on the MiStrEnGTH program at the end of the study. Your involvement in the study will also help us better understand how best to provide stroke services for people living in Queensland and beyond.

7. What are the possible risks and disadvantages of taking part?

There are no foreseeable risks and disadvantages of taking part in this project. The low risk of experiencing negative feelings, such as sadness, when discussing your stroke and any changes you may have experienced after it should be considered.

8. What if I withdraw from this research project?

If you do withdraw your consent during the research project, the research staff will not collect additional personal information from you. The personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

9. Could this research project be stopped unexpectedly?

It is not anticipated that this research project will be stopped unexpectedly.

10. What happens when the research project ends?

At the end of the study the information collected will be analysed and written up for presentation in the scientific community. This may be through peer-reviewed scientific publications or at scientific conferences. If participants would like to receive a written summary of the results of the study they can request this of the research team. Results of the completed study should be available by late 2018.

If you wish to have access to your personal results from any of the tasks, you may contact the investigator named below. You will also be directed to any publications arising from this study.

Part 2 How is the research project being conducted?

11. What will happen to information about the participant?

By signing the consent form you consent to research staff collecting and using personal information about you for the research project. Your privacy and confidentiality will be maintained at all times during this project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. You will be assigned a study number (e.g. SS001). All relevant data collected about you will be labelled with this number and not your name. Information will be stored safely and securely in a locked filing cabinet in the Allied Health Research Collaborative, The Prince Charles Hospital and in a locked filing cabinet in the School of Health and Rehabilitation Sciences Higher Research Degree Room, The University of Queensland. Information regarding your medical history will only be used by those researchers working on the study. The results of all tests will not be published in a way that could reveal your identity. If you wish to have access to your personal results from any of the tasks you may contact the investigator named below.

All data will be stored for 7 years after completion of the study, except for audio recordings made during the study. The audio recordings will be written out in full and stored in paper format for 7 years. Audio recordings will be erased once the analysis is complete.

12. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible. You will be assisted with arranging appropriate medical treatment. All medical treatment required to treat the injury or complication will be free of charge as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted by the Allied Health Research Collaborative and Stroke Services within Metro North Hospital and Health Service. The project is funded by the Health Practitioner Research Major Grant Scheme. Participation in this research is voluntary and you will receive no payments associated with your participation in the project.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of The Prince Charles Hospital, Griffith University, The University of Queensland, and Australian Catholic University. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you have any queries regarding the nature of this research or the procedure, please feel free to contact the research contact person:

Name	**Dr Petrea Cornwell**
Position	**Principal Research Fellow, Allied Health Research Collaborative**
Telephone	**(07) 3139 6112**
Email	petrea.cornwell@health.qld.gov.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	**Mrs Anne Carle**
Position	**Executive Officer, Human Research Ethics & Governance Unit**
Telephone	**(07) 3139 4500**
Email	anne.carle@health.qld.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the Executive Officer, Research and Ethics from the (07) 3139 4500 who will forward their concerns to the Chair, Human Research Ethics Committee.

Participant Consent Form

Patient Group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

I agree to participate in the above named project and in so doing acknowledge that:

- I have been informed as to the nature and extent of any risk to my health or well-being.
- I am aware that, although the project is directed to the expansion of medical knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to me.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that my GP may be informed that I am taking part in the project.
- I understand that, in respect of any information (which may consist of records outside of this hospital) including audiovisual records obtained during the course of the project; confidentiality will be maintained to the same extent as for my Hospital medical records. In the event of any results of the project being published, I will not be identified in any way.
- I agree that, if necessary, my medical records (in respect of my involvement in this project) may be inspected by a Research Assessor. This assessor may be external to but approved by the Hospital, provided that the Assessor does not identify me or my hospital's medical records in any way to a third party.

☐ I consent to being approached to participate in interviews, in addition to the assessments. I do, however, understand that not every participant will be approached to participate in the additional interview.

Patient's name: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Name of Investigator: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Withdrawal of Participation

Patient group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

- I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with The Prince Charles Hospital, Metro North Hospital and Health Service, Griffith University, the University of Queensland, or the Australian Catholic University.

Participant's name (please print): .....

(Signature)..... **Date: _ _ / _ _ _ / _ _ _ _**
DD / MMM /
YYYY

This Withdrawal of Participation should be forwarded to:

Dr. Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital
627 Rode Rd, Chermside

Participant Information Sheet

Carer group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/19**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in this research project: **"Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)".** You have been identified by your family member who has had a mild stroke and is going home as their primary support person, and therefore, you are invited to participate in this research project. The project aims to compare our usual care processes for managing the recovery of individuals with mild stroke to a new allied health-led model of care.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what would be involved should you agree to participate. Knowing what is involved will help you decide if you want to take part in the research. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You and your family member will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project

• Consent to the tests and research that are described

• Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research?

The aim of the study is to compare two models of care for supporting recovery after mild stroke. The first model is the current model of care (described in section 3 of this form) at The Prince Charles Hospital. The second model is anew allied health-led approach. We want to know how each model of care may impact on people with mild stroke. We are interested in their quality of life, general mood, participation in daily activities and community life. We are also interested in knowing how your life may be impacted, including your mood or other aspects of your life. This project will allow us to see which model of care best supports survivors of mild stroke and their family after hospital discharge.

Issues that may impact over time on survivors of mild stroke and their family members include reduced quality of life and depression. The time when a stroke survivor first returns home is an important phase of recovery. Stroke survivors will look to return to all parts of their life in their home and community. Many survivors of *mild stroke* have reported being independent in everyday activities of home. They often report though changes in their emotions and quality of life, as well as a sense of not being prepared mentally or physically to return to their lives in the community. This research intends to compare two model of care to see how well each addresses the needs of survivors of mild stroke and their family, and to inform clinical practice in the area of stroke care.

This research is funded by the Health Practitioner Research Major Grant Scheme.

3. What does participation in this research involve?

Two types of participants will be recruited to the study. The first group is made up of survivors of mild stroke. The second group consists of a close family member or friend who will support them in the first six-months after their stroke. This is the group you would be recruited to in the study. As the identified main carer or support person of a stroke survivor who is participating in the study, we would like to invite you to participate in the study. Your involvement would involve you completing assessments regarding your mood, and how the “carer” role has

affected your life (if at all). We will also ask you to rate your satisfaction with stroke services provided to the person with stroke and yourself. Participants with stroke will be allocated randomly to one of two treatment groups, and you as their carers will be allocated to the same group. One group will receive current usual care, while the second group will receive the new model of care. All participants with stroke will have had a mild stroke and have been admitted to an acute ward at The Prince Charles Hospital.

If you agree to participate in the study, you will need to sign the consent form. A member of the research team will ask you some questions about yourself (e.g. age, relationship to stroke survivor, employment status). The first step of the project will see you complete a number of questionnaires at the time of the stroke survivors discharge from hospital. The questionnaires will look at topics such as your quality of life, mood, and feelings of carer strain. You will also be asked to rate your satisfaction with the stroke services received. The total time to complete the assessments would be around ½ hour. Assessments may be conducted at The Prince Charles Hospital prior to the person with stroke leaving hospital for the initial session or in your home if required. The questionnaires will be completed again at 1-, 3- and 6- months after hospital discharge. At these times a member of the research team will come to your home to assist with completing the questionnaires. If you happen to be attending a hospital clinic appointment at these times the session could be done at the hospital. These sessions will be organised at a time convenient to you.

In addition, you may be asked to participate in an interview at 9- months after hospital discharge. This interview will discuss your relationship with the stroke survivor, changes in your home environment that may have happened after the stroke, and satisfaction with care. This interview will be conducted on a separate day to the questionnaires, at a time that is convenient to you. The interview will take place at your home or at a mutually agreed upon location. You will be given the choice to participate in the interview and the questionnaire, or just the questionnaire.

After the initial assessment you and the individual with stroke will receive either current usual care or the new allied health-led service. If you are allocated to the usual care group, services will be provided by the treating health team. This group will be referred to as the “standard care” group. Usual care for mild stroke patients and yourself includes some or all of the following:

1. education related to stroke by a Stroke Nurse or Allied Health Professional;
2. referral to see local General Practitioner (GP), with a hospital report sent directly to your nominated GP to tell them about your stroke and recommendations for care;
3. follow-up appointment at The Prince Charles Hospital outpatient clinic between 1 and 3 months post-hospital discharge;
4. provision of information for local peer stroke support groups; and
5. referral to or provision of information on local community-based programs and services (e.g. home help, meals on wheels).

If you are allocated to the allied health-led service group be referred to as the "MiStrEnGTH" group. This new model of care is being trialled in this research. You will receive the same services as "standard care" plus up to 5 phone calls over the first 6-months after the stroke survivors' hospital discharge. These phone calls will be checking how the person with stroke and yourself are both managing following their stroke and return home.

You will receive phone calls at the following times:

- 1-week after discharge from hospital
- 4-weeks after discharge from hospital
- 8-weeks discharge from hospital, and
- then two more phone calls can be scheduled between 2- and 6-months after your stroke. The timing of these phone calls will be decided you and the research therapist.

4. What are the possible risks and side effects of taking part?

There are no to minimal risks or side effects from taking part in this study. For all carers of stroke survivors, basis information will be collected from you including age, gender, education level and relationship to participant with stroke. The assessment tasks you will be required to complete during various stages of the study are described in the table below. The tasks are designed to assess the quality of life, client mood, carer strain. They should not cause significant discomfort.

You may be inconvenienced in terms of the time commitment required to participate in the study; however every effort will be made to schedule sessions at times that are convenient to you. If necessary, the assessments can be completed over a number of sessions.

The risk of harm to you is considered extremely low. Some of the questions asked may result in you feeling particular emotions. You may feel upset, angry or other emotions during the

assessment and/or interview relating to how stroke has impacted the life of your family member/friend and you. Such responses for you are likely part of an adjustment process to supporting someone with stroke. For stroke survivor such feelings may be due to an adjustment process, or a direct impact of the stroke. The research therapist will talk with you about these emotions and provide strategies or ideas to manage these emotions with a view to reducing their impact on you. For all participants (individuals with stroke and you as the carer), the research team will seek to manage this risk. This may involve them assisting you to connect with appropriate supports (e.g. your GP, or phone based services such as Lifeline).

Carer Participant assessment Tasks – Total time to complete ½ hours			
Assessment of Quality of Life - 4D (AQoL-4D)	You will complete a 20 item questionnaire that asks questions about independent living, mental health, coping, relationships, pain, and senses.	5 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Depression Anxiety Stress Scale – 21 (DASS-21)	The DASS-21 is a 21-item questionnaire that requires you to respond to statements relating to symptoms of depression, anxiety and stress.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Carer Strain Index (CSI)	The CSI is a 13-item questionnaire that asks questions about the impact of taking on a carer or support role. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time.	<10 minutes	Discharge, 1 month, 3 months, & 6 months post discharge
Service Satisfaction VAS	You will be asked to rate your satisfaction with the care you've received related to your stroke. On a line you will be asked to indicate you level of satisfaction where 0=worst possible care, and 10=best possible care.	1-2 minutes	Discharge, 1 month, 3 months, & 6 months post discharge

5. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your

routine treatment or that of the participant with stroke, your relationship or that of the participant with stroke with those treating team or hospital.

6. What are the possible benefits of taking part?

We cannot promise that you or the participant with stroke will receive any benefits from this research above that which would be gained from usual clinical practice. Through the project your quality life, general mood and well-being, and feelings of carer strain will be monitored. Should you experience changes to your mood or well-being the research therapist will provide advice in regards on accessing support for these problems. If the phone calls received by the MiStrEnGTH group are found to be beneficial above 'standard care", participants in the standard care group will receive a phone call consultation based on the MiStrEnGTH program at the end of the study. Your involvement in the study will also help us to better understand how best to provide stroke services for people living in Queensland and beyond.

7. What are the possible risks and disadvantages of taking part?

There are no foreseeable risks and disadvantages of taking part in this project. The low risk of experiencing negative feelings, such as sadness, when discussing the survivor's stroke and any changes you may have experienced after it should be considered.

8. What if I withdraw from this research project?

If you do withdraw your consent during the research project, the research staff will not collect additional personal information from you. The personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the sponsor up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project.

9. Could this research project be stopped unexpectedly?

It is not anticipated that this research project will be stopped unexpectedly.

10. What happens when the research project ends?

At the end of the study the information collected will be analysed and written up for presentation in the scientific community. This may be through peer-reviewed scientific

publications or at scientific conferences. If participants would like to receive a written summary of the results of the study as a whole they can request this of the research team. Results of the completed study should be available by late 2018.

If you wish to have access to your personal results from any of the tasks, you may contact the investigator indicated below. You will also be directed to any publications arising from this study.

Part 2 How is the research project being conducted?

11. What will happen to information about the participant?

By signing the consent form you consent to research staff collecting and using personal information about you for the research project. Your privacy and confidentiality will be maintained at all times during this project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law. You will be assigned a study number (e.g. SS001) and all relevant data collected about you will be labelled with this number and not your name. Information will be stored safely and securely in a locked filing cabinet in the Allied Health Research Collaborative, The Prince Charles Hospital and in a locked filing cabinet in the School of Health and Rehabilitation Research Higher Degree Room, The University of Queensland. The results of all tests will not be published in a way that could reveal your identity. If you wish to have access to your personal results from any of the tasks you may contact the investigator indicated below.

All data will be stored for 7 years after completion of the study, except for audio recordings made during the study. The audio recordings will be written out in full and stored in paper format for 7 years, but the audio recordings will be erased once the analysis is complete.

12. Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible. You will be assisted with arranging appropriate medical treatment. All medical treatment required to treat the injury or complication will be free of charge as a public patient in any Australian public hospital.

13. Who is organising and funding the research?

This research project is being conducted by the Allied Health Research Collaborative and Stroke Services within Metro North Hospital and Health Service. The project is funded by the Health Practitioner Research Major Grant Scheme. Participation in this research is voluntary and you will receive no payments associated with your participation in the project.

14. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of The Prince Charles Hospital, Griffith University, The University of Queensland, and Australian Catholic University. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15. Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you have any queries regarding the nature of this research or the procedure, please feel free to contact the research contact person:

Name	**Dr Petrea Cornwell**
Position	**Principle Research Fellow, Allied Health Research Collaborative**
Telephone	**(07) 3139 6112**
Email	petrea.cornwell@health.qld.gov.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	**Mrs Anne Carle**
Position	**Executive Officer, Human Research Ethics & Governance Unit**
Telephone	**(07) 3139 4500**
Email	anne.carle@health.qld.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact the Executive Officer, Research and Ethics from the (07) 3139 4500 who will forward their concerns to the Chair, Human Research Ethics Committee.

Participant Consent Form

Carer Group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

I agree to participate in the above named project and in so doing acknowledge that:

- I have been informed as to the nature and extent of any risk to my health or well-being.
- I am aware that, although the project is directed to the expansion of medical knowledge generally, it may not result in any direct benefit to me.
- I have been informed that my refusal to consent to participate in the study will not affect in any way the quality of treatment provided to me.
- I have been informed that I may withdraw from the project at my request at any time and that this decision will not affect in any way the quality of treatment.
- I have been advised that the Executive Director, The Prince Charles Hospital, on recommendation from The Prince Charles Hospital Metro North Hospital and Health Service Human Research Ethics Committee has given approval for this project to proceed.
- I am aware that I may request further information about the project as it proceeds.
- I am aware that my GP may be informed that I am taking part in the project.
- I understand that, in respect of any information (which may consist of records outside of this hospital) including audiovisual records obtained during the course of the project; confidentiality will be maintained to the same extent as for my Hospital medical records. In the event of any results of the project being published, I will not be identified in any way.
- I agree that, if necessary, my medical records (in respect of my involvement in this project) may be inspected by a Research Assessor. This assessor may be external to but approved by the Hospital, provided that the Assessor does not identify me or my hospital's medical records in any way to a third party.

☐ I consent to being approached to participate in interviews, as well as assessments. I do, however, understand that not every carer will be approached to participate in the additional interview.

Patient's name: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Name of Investigator: .....Signature: ..... Date:_ _ / _ _ _ / _ _ _ _

DD / MMM / YYYY

Withdrawal of Participation

Carer group – The Prince Charles Hospital

HREC No:	**HREC/15/QPCH/18**
Project Title:	Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiSTRENGTH)
Name of Researchers:	Dr Petrea Cornwell, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire & Ms Tenelle Hodson
Sponsor Details:	HP Research Major Grant Scheme

- I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with The Prince Charles Hospital, Metro North Hospital and Health Service, Griffith University, the University of Queensland, or the Australian Catholic University.

Participant's name (please print): .....

(Signature)..... **Date: _ _ / _ _ _ / _ _ _ _**
DD / MMM /
YYYY

This Withdrawal of Participation should be forwarded to:

Dr. Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital
627 Rode Rd, Chermside
Queensland, Australia 4032

Appendix 6: Ethics Approval Documentation

Please note these are a copy of the original documents.

Enquiries to: RGOTPCH@health.qld.gov.au
Office Ph: (07) 3139 6198
(07) 3139 6687
Amendment Ref: AM02

Queensland Government

28 June 2016

Research Governance Office
Metro North Hospital and Health Service
The Prince Charles Hospital
Building 14
Rode Road, Chermside QLD 4032

Dr Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital

Dear Dr Cornwell,

SSA/15/QPCH/248
HREC/15/QPCH/18: Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)

This is to acknowledge that we have received correspondence regarding your Ethics approval for amendments to your study, as stated in The Prince Charles Hospital HREC letter dated 30 May 2016.

I am pleased to advise that, as The Prince Charles Hospital Governance Officer, I have reviewed and acknowledge the amendments submitted.

This information has been filed in your site file for our site records.

Yours truly,

Digitally signed by Dr Tania Crough
DN: cn=Dr Tania Crough, o, ou, email=Tania.Crough@health.qld.gov.au, c=AU
Date: 2016.06.28 13:00:19 +10'00'

Dr Tania Crough
Governance Officer
Research, Ethics & Governance Office
The Prince Charles Hospital

Enquiries to: RGOTPCH@health.qld.gov.au
Office Ph: (07) 3139 4198
(07) 3139 4687
Our Ref: AM03

Queensland Government

28 June 2016

Research Governance Office
Metro North Hospital and Health Service
The Prince Charles Hospital
Building 14
Rode Road, Chermside QLD 4032

Dr Petrea Cornwell
Allied Health Research
Collaborative
The Prince Charles Hospital

Dear Dr Cornwell,

SSA/15/QPCH/248
HREC/15/QPCH/18: Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)

I am pleased to advise that, as The Prince Charles Hospital Governance Officer, I have reviewed the amended documents submitted, as stated in TPCH HREC letter dated 30 May 2016, and have granted approval for the following:

- Site Specific Participant Information Sheet & Consent Form (Patient) – Version 2, dated 8 June 2016 (Based on Master Version 4, dated 12 April 2016)
- Site Specific Participant Information Sheet & Consent Form (Carer) – Version 3, dated 8 June 2016 (Based on Master Version 4, dated 12 April 2016)

This information has been filed in your site file for our site records.

Yours truly,

Digitally signed by Dr Tania Crough

Dr Tania Crough
Governance Officer
Research, Ethics and Governance Unit
The Prince Charles Hospital

Queensland Government

MEMORANDUM

Metro North Hospital and Health Service
Royal Brisbane and Women's Hospital

To:	**Dr Petrea Cornwell, Principal Research Fellow, Allied Health Collaborative, The Prince Charles Hospital**		
Cc:	**Dr Andrew Wong, Department of Neurology, RBWH**		
From:	Anitha Dinesh Research Support Officer, RBWH	**Contact No:** **Fax No:**	3646 2377 3646 2355

Research	**Protocol:**	**HREC/15/QPCH/18**
	Title:	**Improving the recovery outcomes for people with Mild STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)**
	Principal Investigator:	**Dr Petrea Cornwell**
Subject	Acknowledgement of document reviewed	**RGO File Ref:** SSA/16/QRBW/46

The following document(s) have been received and sanctioned by the Research Governance Office of the Metro North Hospital and Health Service- Royal Brisbane and Women's Hospital.

Document	*Version*	*Date*
Cover letter to RBWH RGO		8 June 2016
TPCH HREC amendment approval letter		30 May 2016
Study Protocol – clean and tracked	4.0	12 April 2016
RBWH Participant Information Sheet and Consent Form (Patient) (Based on Master Participant Information Sheet and Consent Form (Patient) V4.0 dated 12 April 2016) – clean and tracked	2.0	8 June 2016
RBWH Participant Information Sheet and Consent Form (Carer) (Based on Master Participant Information Sheet and Consent Form (Carer) V4.0 dated 12 April 2016) – clean and tracked	2.0	8 June 2016

By supplying the above mentioned document(s) you have complied with the principles and practices set out in the Australian Code for the Responsible Conduct of Research (2007 Universities Australia, updated 2014) and the ICH Harmonised Tripartite Good Clinical Practice Guidelines (GCP, E6)

This office doesn't require hard copies of amendments. Please email electronic copies to RBWH-RGO@health.qld.gov.au

Research Governance Forms can now be found at the new MNHHS Research Web site:
https://www.health.qld.gov.au/metronorth/research/ethics-governance/post-approval-reporting/default.asp

Please note that original conditions of approval still apply. If you have any questions relating to this authorisation please contact the Research Governance Officer on 3646 8579 or email RBWH-RGO@health.qld.gov.au. Please remember to send annual reports to your HREC and then to the RGO along with the HREC approval letter. The study will remain open on our data base until we receive your final report and a letter from the HREC stating your research has been closed.

I wish you continued success with your research.

Yours sincerely

Anitha Dinesh

Anitha Dinesh
13/06/16

Enquiries to: [redacted]
Office File: [redacted]
Amendment Ref: [redacted]

Queensland Government

10 November 2016

The Prince Charles Hospital
Human Research Ethics Committee
The Prince Charles Hospital
Building 14
Rode Road,
Chermside QLD 4032

Dr Petrea Cornwell
Allied Health Research Collaborative
The Prince Charles Hospital

Dear Dr Cornwell,

Re: HREC/15/QPCH/18: Improving the recovery outcomes for people with MIld STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)

I am pleased to advise that The Prince Charles Hospital Human Research Ethics Committee (TPCH HREC) reviewed the amendments submitted and upon recommendation, the Chair has granted approval for the following:

- Protocol Version 5 dated 12 October 2016
- Occupational Gaps Questionnaire Version 1.0/2013

This information will be tabled at the HREC meeting on 1 December 2016 for noting.

A copy of this approval must be forwarded to each of the Principal Investigators at each site who should provide a copy to their own Hospital & Health Service Research Governance Officer/s or Delegated Personnel, along with updated Site Specific documentation, for CEO or Delegate authorisation for each site.

List of approved Sites:

No.	Site
1.	The Prince Charles Hospital
2.	Royal Brisbane & Women's Hospital

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, *NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Please be advised that in the instance of an investigator being a member of the HREC, they are absented from the decision making process relating to that study.

On behalf of the Human Research Ethics Committee, I would like to wish you every success with your research endeavour.

Yours truly,

Anne Carle
Executive Officer
Research, Ethics and Governance Unit
The Prince Charles Hospital

THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title:	Improving the Recovery Outcomes for People with Mild STRoke: ENhancing and Guiding Transition Home (MiStrEnGTH)
Chief Investigator:	Dr Petrea Cornwell
Supervisor:	None
Co-Investigator(s):	Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Andrew Wong, Ms Leah Thompson, Dr Angela Maguire
School(s):	Allied Health, PCH; UQ SHRS
Approval Number:	2018000021
Granting Agency/Degree:	HP Research Major Grant Scheme
Duration:	6th September 2018

Comments/Conditions:

Expedited review on the basis of approval from The Prince Charles Hospital HREC dated 31/08/2015 & 11/12/2015.

Note: If this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:
Medical Research Ethics Committee
This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Signature _____ Date 14-1-16